THE WORK OF SPOUSAL CAREGIVING IN HEART FAILURE

A Dissertation in

Nursing

by

Lisa A. Kitko

© 2010 Lisa A. Kitko

Submitted in Partial Fulfillment
of the Requirements
for the Degree of

Doctor of Philosophy

August 2010
The dissertation of Lisa A. Kitko was reviewed and approved* by the following:

Judith E. Hupcey
Associate Professor of Nursing
Professor-in-Charge of Graduate Programs in Nursing
Dissertation Advisor
Chair of Committee

Janice Penrod
Associate Professor of Nursing

Susan J. Loeb
Assistant Professor of Nursing

Robert W. Schrauf
Associate Professor of Applied Linguistics
Faculty Affiliate of the PSU Gerontology Center

*Signatures are on file in the Graduate School
ABSTRACT

Background: The number of patients with heart failure is at epidemic proportions. Heart failure significantly changes and impacts life for the patient and family. Heart failure requires complex home medical management that is often interrupted with frequent hospital admissions for acute exacerbations. While providing this critically important care, informal caregivers face significant threats to their own health, including psychological, physical, and financial distress. Little is known regarding the “work” of caregiving. There were no identified studies in the literature that evaluated the spousal caregiving experience over time in the context of the unpredictable and uncertain illness progression of heart failure.

The purpose of this study was to define the types of work experienced in long term spousal caregiving in older adults across the illness progression of heart failure utilizing qualitative methodology. The goal of this study was to gain a deeper understanding of the types of work in spousal caregiving specifically defining the types of work manifested over the course of 12-14 months of caregiving. The second goal of this study was to generate a middle range theory of spousal caregiving in heart failure.

Methods: This study was a qualitative secondary analysis of a larger longitudinal study on the palliative care needs of older patients with heart failure and their spousal caregivers (Hupcey, PI). The in-depth serial interview data of 20 spousal caregivers collected monthly over a period of 12-14 months were analyzed utilizing the tenets of qualitative grounded theory methodology. The spousal caregivers ranged in age from 46-78 with a mean age of 67. The care recipients ranged in age from 62-79 with a mean age
of 70. Fourteen of the caregivers were female and 6 were male. Length of time in the caregiving role from the beginning of the study ranged from 2 months to 9 years.

**Results:** The types of work experienced varied dynamically each month over the 12-14 month period. The seven main thematic concepts, *work of providing care, work of living with the illness, the work of navigating the system, the work of maintaining self, the work of managing the household, the work of vigilance,* and, *the work of normalcy,* support the basic social process of caring for a spouse across the illness progression of heart failure and informed the emergence of the core variable of *Committed Obligation* and subsequent theory of the *Process of Committed Obligation*.

**Conclusion:** The results of this study demonstrate that the needs of the couples, especially the caregiver, require more than a brief contact with the healthcare provider and healthcare providers should recognize cues in the clinical encounters that could lead to specific needs driven interventions. The findings of this study illustrate that the caregiver moves with the spouse during the course of the illness and when there is an exacerbation or instability the needs of the caregiver escalate in tandem with the care recipient but may be manifested in different ways. Caregivers should be assessed for unmet needs throughout the course of heart failure not just at exacerbations or hospitalizations. Caregivers and patients with advanced heart failure may benefit from specific models of supportive care throughout the trajectory of heart failure. Comprehensive models of care, which focus on quality of life, symptom control, and
psychosocial support for patients and their caregivers in the midst of active treatment should be developed.
TABLE OF CONTENTS

LIST OF FIGURES ........................................................................................................ ix

LIST OF TABLES ............................................................................................................ x

ACKNOWLEDGEMENTS ................................................................................................ xi

Chapter 1 Introduction .................................................................................................. 1
  Statement of Problem ................................................................................................ 3
  Purpose of Study ......................................................................................................... 12
  Conceptual Framework ............................................................................................. 12
  Research Question ..................................................................................................... 13
  Theoretical Definitions ............................................................................................... 13
  Significance of Study ................................................................................................. 14

Chapter 2 Literature Review ......................................................................................... 17
  Introduction ................................................................................................................ 17
  Theoretical Frameworks ............................................................................................. 17
    Symbolic Interactionism ......................................................................................... 18
    Theory of Illness Trajectory .................................................................................. 22
    Corbin and Strauss Chronic Illness Management .................................................. 27

  Conceptual Discussion ............................................................................................... 34
    Spousal Caregiving and Chronic Illness ................................................................. 34
      The Physical Impact of Caregiving ...................................................................... 36
      The Psychological Impact of Caregiving .............................................................. 39
      The Financial Consequences of Caregiving ....................................................... 41
      The Social Consequences of Caregiving ............................................................. 42
      The Positive Aspects of Caregiving ..................................................................... 43
      The Physical Impact of Caregiving on the Older Adult ...................................... 44
      The Psychological Impact of Caregiving on the Older Adult ......................... 46

  Caregiving and Heart Failure .................................................................................. 48
    Professional Support of Heart Failure Patients and Caregivers ......................... 49
    Social Support for Heart Failure Caregivers ......................................................... 51
    Caregiver Burden and Heart Failure ..................................................................... 52
    Life Sustaining Interventions in Acute Heart Failure ............................................ 54
LIST OF FIGURES

Figure 1.1: Prototypical Death Trajectories.................................................................6
Figure 2.1: Conditional Matrix: Transactional System Between Spouses......................32
Figure 4.1: The Process of Committed Obligation. .......................................................115
Figure 5.1: Conditional Matrix: Transactional System Between Spouses......................115
Figure 5.2: The Process of Committed Obligation. .......................................................115
LIST OF TABLES

Table 4-1: Participant Demographics. ...........................................................................82
ACKNOWLEDGEMENTS

I wish to acknowledge and thank the following people for the support shown for me over the course of my doctoral work. First and foremost, I thank my husband, my parents, and my children, Nicholas and Alex. I cannot express the gratitude I have for the support they have all given me during this journey.

Judy Hupcey has been my mentor and advisor. Judy has introduced me to her areas of research which then stimulated my path of research. Judy has been steadfast in her support not only through my doctoral work but also through my master’s work. I am so grateful to Judy for her mentoring, support, and friendship. I would not be to this point in my career without her and look forward to continued collaborations in the future.

I want to also thank Janice Penrod. Janice initially encouraged me to pursue my doctoral degree. Janice has been a mentor throughout my career and spurred my interest in the possibility of a research career.

Susan Loeb and Bob Schrauf were members of my dissertation committee and each have provided insightful guidance. I have been influenced by everyone I have encountered at Penn State and am very grateful for all of the experiences during my doctoral education. I would especially like to thank my cohort of classmates, Mindy Steis, Kim Fenstermacher and Janet Fogg who have offered so much inspiration and support throughout the years and have become great friends.
Chapter 1

Introduction

The number of patients with heart failure is at epidemic proportions resulting in major clinical, social, and economic problems in the United States. Over 5.8 million Americans are living with heart failure (American Heart Association (AHA), 2010). As a leading cause of morbidity and mortality, heart failure contributes to more than 290,000 deaths each year (AHA, 2010). Despite recent advances in therapy, the one year mortality rate is high, with one in five dying (AHA, 2010). Dargie and McMurray (1994) describe heart failure as a “malignant condition” that increases in prevalence with age. The survival rate is worse than for many types of cancer such as large bowel, prostate and bladder (Stewart, MacIntyre, Hole, Capewell, & McMurray, 2001). Improved initial care of patients with acute coronary events, increased life expectancy, and aging of the baby boom generation are all factors that are contributing to the development of more cases of heart failure than at any given time in the past (AHA, 2010). The impact of this devastating condition is also reflected in economic trends. Heart failure ranks among all Medicare diagnostic groups as the most costly of medical diagnoses (AHA, 2010). According to the AHA (2010) the direct and indirect costs of caring for heart failure is estimated to be greater than thirty-seven billion dollars.

Heart failure is the final common pathway in the progression of a number of diseases that injure the heart. Disease processes such as coronary artery disease, hypertension, valvular disease, and infection can lead to heart failure. Regardless of the
causative illness, heart failure results in the inability of the heart to pump effectively enough to meet the metabolic needs of the body. The compensatory mechanisms become maladaptive over time, and lead to the progression of heart failure. Acute exacerbations and progression of symptoms are common and this process usually becomes disabling.

Patients with heart failure may range in disease severity from mild to very severe states. The New York Heart Association (NYHA) functional classification system is the most common method utilized by health care providers (Porth, 2008). Patients are classified in one of four classifications based on level of symptoms in response to activity. Class I describes patients who are asymptomatic with ordinary exertion. Class II describes patients who are symptomatic with ordinary physical exertion. Class III describes patients who are symptomatic with less than ordinary physical exertion. Patients with Class IV are symptomatic at rest. Patients with advanced disease are generally Class III and IV and may require mechanical circulatory support, continuous inotropic infusions, and cardiac transplantation (Porth, 2008) as well as more frequent hospitalizations for disease management.

Patients with heart failure report worse physical, role, and social functioning than patients with any other chronic medical condition (Stewart et al., 1989). This is confirmed by a small sample of older heart failure patients who reported depression (61%), poor quality of life (50%) and pain (46%) (Aldred, Gott, & Gariballa, 2005a). There is also widespread agreement among health care professionals that cardiac illness is a major life stressor that exerts long-term effects on the psychological health and quality of life of the entire family (Dracup et al., 2004; Evangelista et al., 2002).
Statement of Problem

Heart failure significantly changes and impacts life for the patient and family. The needs of patients with heart failure are extensive when you take into consideration the functional limitations imposed by a failing heart. Four out of five heart failure patients have five or more noncardiac comorbidities such as: chronic obstructive lung disease, hypertension, diabetes, anemia, sleep disordered breathing, and depression (Artinian, Artinian, & Saunders, 2004). The average heart failure patient takes six medications a day (Kutzleb & Reiner, 2006). Coping with a disease like heart failure and the lifestyle changes required of the patient and family members is a day-to-day struggle (Martensson, Dracup, & Fridlund, 2001). The functional limitations, as a direct result of a failing heart, and the fact that most patients with heart failure are greater than 65 years of age (AHA, 2010), dramatically increases the patient’s needs at home. In most situations, the majority of informal care is provided in the home setting with care provided by family members, usually the spouse (Harkness & Tranmer, 2007). A 2008 Institute of Medicine report, *Retooling for an Aging America: Building the Health Care Workforce*, emphasizes the need to prepare professionals, paraprofessionals, and especially informal family caregivers for an older U.S. population. It is essential to more fully understand the experiences of the caregivers so that nurses can support and prepare these caregivers.

There are 44 million Americans providing care for relatives with chronic illnesses at home and nearly 5 million may be caring for patients with heart failure (National Alliance for Caregiving and AARP, 2004). Family members often assume caregiving
responsibilities with little preparation for the role and little ongoing support. In its report *Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving*, the AARP estimated the economic value of family caregiving in 2006 at $350 billion, exceeding the total amount spent in 2005 by either Medicare ($342 billion) or Medicaid ($300 billion)(Gibson & Houser, 2007).

Heart failure requires complex home medical management that is often interrupted with frequent hospital admissions for acute exacerbations. Patients with heart failure are managed toward the goals of symptom reduction, maintenance of clinical stability, and prolonged survival. This at home management for heart failure includes complex instructions regarding exercise, symptom management, multiple daily doses of oral medication that may require altered doses based on daily weight changes, as well as detecting early signs of heart failure decompensation such as shortness of breath, decreasing appetite, or weight gain (D’Alto, Pacileo, & Calabro, 2003). The care provided by the informal caregiver includes a combination of physical, practical, and emotional care (Hauser & Kramer, 2004) that changes over the course of an illness and increases in intensity as the patient’s health declines (Weitzner, Haley, & Chen, 2000). Over one-fourth of the caregivers in one study reported difficulty managing the sodium restrictions imposed on the patient as well as the monitoring for signs and symptoms of failure (Pressler et al., 2009). The duration of caregiving is often prolonged extending over months to years (Lunney, Lynn, & Hogan, 2002).

While providing this critically important care, informal caregivers face significant threats to their own health, including psychological, physical, and financial distress
(Rabow, Hauser, & Adams, 2004). Shanks-McElroy and Strobino (2001) reported that caregivers experience a one-third increase in negative health symptoms after assuming caregiving responsibilities. Spousal caregivers reported more days of illness because of infectious disease, primarily upper respiratory tract infections, than noncaregivers (Esterling, Kiecolt-Glaser, & Glaser, 1996). Given these health changes, it is not surprising that caregivers have a higher risk of mortality than noncaregivers. In a landmark longitudinal study titled the “Caregiver Health Effects Study,” Schulz and Beach (1999) found that 392 spousal caregivers who were experiencing strain had mortality risks that were 63% higher than did 427 age and gender matched persons who were not caregivers. Harding and Higginson (2003) captured the significance of threats to caregivers’ health as they warned against conceptualizing informal caregivers only as co-providers of care and excluding professional attention to their equally important needs as care recipients.

Based on the statistics given in the seminal work by Schulz and Beach (1999), amazingly little is known about the impact of heart failure on the informal caregivers from their own perspective. Also, research on this topic to date has not been longitudinal and therefore, neither captures the unpredictable illness trajectory of heart failure nor the changes in the caregiving experience over time. Such information is essential to planning how end-of-life support in heart failure can be more appropriately managed to ensure the needs of the caregiver and patient are met.

There is also widespread recognition that end-of-life care in heart failure is not adequate (Gibbs, Addington-Hall, Simon, & Gibbs, 1998; Hanratty et al., 2002; Ward,
and that these patients do not receive end-of-life care comparable to those dying from cancer. A qualitative study comparing the quality of life of patients with lung cancer and advanced heart failure found that cardiac patients received less health, social, and palliative care services, and that care was often poorly coordinated (Murray et al., 2002). The researchers concluded that current end-of-life care is prioritized on diagnosis and not based on need. These finding may be attributed to the fact that heart failure is often treated as an acute illness until the time of death. The aggressive curative approach typical to heart failure may not seem congruent with palliative care services and may also negatively impact the caregiving experience.

An additional contributing factor is the unpredictability of the illness trajectory specific to heart failure. Variations in the terminal illness or death trajectories were initially proposed in terms of two properties, duration of the terminal trajectory and shape of the trajectory (Glaser & Strauss, 1965). From this initial conceptualization, Field and Cassel (1997) described three illness trajectories. The first trajectory is the sudden death, unexpected cause which is marked by a stable health status over time and then a sharp decline to death as from a fatal car accident or massive myocardial infarction. With death unexpected, there is little need or time for end-of-life services (Figure 1.1). The second trajectory described by Field and Cassel (1997) is the steady decline with a short terminal phase. This trajectory is marked by a stable health status and then a fairly predictable steady decline, such as many terminal cancer patients experience (Figure 1.1). In this trajectory there usually is a shift in the focus of care in which no further curative treatments are warranted followed by an infusion of end-of-life services. Field and
Cassel (1997) described the third death trajectory as one manifested with fairly long periods of chronic illness marked by exacerbations or crises. In most cases acute, curative treatments continue until the end-of-life and death is usually unexpected with the patients and families receiving little to no end-of-life services (Figure 1.1).

A. Sudden Death from an Unexpected Cause

![Graph A: Sudden Death from an Unexpected Cause](image)

B. Steady Decline from a Progressive Disease with a "Terminal" Phase

![Graph B: Steady Decline from a Progressive Disease with a "Terminal" Phase](image)

C. Advanced Illness Marked by Slow Decline with Periodic Crises and "Sudden" Death

![Graph C: Advanced Illness Marked by Slow Decline with Periodic Crises and "Sudden" Death](image)
Heart failure does not easily fit into one of these death trajectories due to the unpredictable course of the disease process. In contrast to a relatively predictable terminal illness trajectory such as advanced cancer, there are multiple death trajectories manifested in people with heart failure, and adding to the uncertainty, no single trajectory captures the totality of the experience (Goodlin et al., 2004; Hupcey, Penrod, Fenstermacher, & Boehmer, 2008). In the past, the heart failure trajectory was characterized by a slow steady decline in functional status with increasing severity and frequency of symptoms over time, punctuated by periods of unpredictable exacerbation from which patients may or may not recover (Gott et al., 2007; Stuart, 2007; Murray et al., 2002). The true unpredictable trajectory of heart failure was only recently described by Gott and colleagues (2007). They followed 27 heart failure patients until death and found five different trajectories based on the patient’s physical limitation over the course of up to 24 months prior to their death. Their death trajectories included ones that were similar to frailty, terminal cancer, and typical heart failure, but also included one showing
an improvement before death and one with fluctuations but without a downward decline before death.

Hupcey et al. (2008) followed 46 patients living with (not necessarily dying from) heart failure over the course of 12-14 months. They found that in addition to the typical illness trajectory of a slow insidious decline punctuated with crises, ultimately leading to an “unexpected” death, there were other prominent heart failure trajectories. The trajectories included, sudden death from heart failure; living with a slow decline; living with heart failure while awaiting a heart transplant; living with heart failure following placement of a device or change in medical management leading to medical stability; and the typical heart failure trajectory with hospice care in which death is expected. One of the key findings in the Hupcey et al. (2008) study was that patients do not necessarily remain in one trajectory throughout the illness but could be in various trajectories throughout the course of the disease compounding the uncertainty experienced by the patient and caregiver.

Throughout the various trajectories for heart failure, family caregivers are a vital factor in both patient disease management and maintaining or improving quality of life. Caregivers encourage patients in self care, monitor patient adherence to the treatment plan, arrange and transport the patient to multiple medical appointments, continually monitor for signs of decompensation (Pattenden, Roberts, & Lewin, 2007), assist patients in reducing their sodium intake, alter grocery shopping patterns to accommodate sodium and fluid restrictions, and take on new roles to accommodate the patient’s functional decline (Clark & Dunbar, 2003). Caregiving consists of not only the observable physical
care mentioned above but also an unseen sense of constant surveillance and assessment of health status and needs. Clark and colleagues (2007) aptly differentiated these processes as “invisible care activities” and “visible care activities”.

Caregiving is a complex process as the process of managing an illness occurs simultaneously with managing a personal life. The management of home care as well as the illness itself can have a dramatic impact on the lives of married couples. Spousal caregivers provide care over longer periods of time and are less likely to place the recipient in long term care facilities as compared to other types of caregivers such as children (Dillehay & Sandys, 1990). The length of caregiving commonly extends five years or longer with a range of 5.8 to 7.4 reported in the literature (Lindgren, 1990; Robinson, 1990).

Pearlin and Aneshensel (1994) and Lindgren (1993) referred to the process of caregiving as a “career,” with a key construct in the caring career being change over time. The change may involve alterations in social relationships and level of activities. Change is also viewed as transitions in the caregiving career as the recipient passes through various illness trajectories.

Conceptualizing caregiving as a “career”, it is also important to note how caregiving differs from the traditional use of the term career as it relates to an occupation. The first key distinction is that caregiving usually begins insidiously. According to Pearlin and Aneshensel (1994), people can easily identify how long a relative has been impaired but have a difficult time establishing the time they identified themselves as caregivers. Caregiving is also different from an occupational career in the sense that
caregiving is unplanned and is not viewed by as most as an elective role. One does not plan on caregiving, have any formal preparation for the role so caregiving is an “unexpected career” (Pearlin & Aneshensel, 1994).

The role of caregiving was more aptly conceptualized by Corbin and Strauss (1988) as “work”. The authors view the work of managing an illness as a complex process. The work also varies as the illness changes over time and each type of work has various associated tasks. Corbin and Strauss (1988) define work as: “a set of tasks performed by an individual or couple to carry out a plan of action designed to manage one or more aspects of the illness.”

Other than the seminal work by Corbin and Strauss (1988), little is known regarding the “work” of caregiving as part of these activities. Wrubel and Folkman (1997) described the observational work that carers engage in and the awareness they develop of the patient’s state of health. However, this was a study of men living with AIDS who were relatively young (median age 40 years). Aspects of caregiving are likely to be markedly different in the context of an older population.

In order to gain an understanding of the types of work experienced in long term spousal caregiving in older patients across the illness progression of heart failure it is imperative to study this phenomenon from their perspective, using methods that address the experience of providing care over the course of the illness. Identifying the types work experienced by the caregiver across the course of heart failure is crucial in developing meaningful interventions that can be utilized by the caregiver. The caregiving experience is poorly explicated in the literature in general and especially in the context of heart
failure, it is essential to gain a better understanding of the work involved across the caregiving course of heart failure.

**Purpose of the Study**

The purpose of this study is to define the types of work experienced in long term spousal caregiving of older patients across the illness progression of heart failure. Caring for a spouse with heart failure is very dynamic in nature with changes occurring over time. This complex experience is best captured through qualitative inquiry that is longitudinal in design. This study is part of a larger longitudinal study on the palliative care needs of older patients with heart failure and their spousal caregivers [AHA, Pennsylvania/Delaware Affiliate Grant-in-Aid Program 2006/2008 (Hupcey PI)]. The primary goal of this study is to gain a deeper understanding of the types of work experienced in spousal caregiving of older patients across the illness progression of heart failure specifically defining the types of work manifested over the course of 12-14 months of caregiving. Identifying the types of work manifested over time will be the initial step to gaining a better understanding of what types of nursing interventions may be appropriate to meet the needs of caregiver. The second goal of this study is to generate a middle range theory of spousal caregiving in heart failure. It is imperative to study this phenomenon from the caregiver perspective, using methods that address the progressive course of the illness over time.

**Conceptual Framework**

The theoretical basis for this study is the theoretical framework developed by Corbin and Strauss (1988) in the book “Unending Work and Care.” Trajectory and work
are the central concepts of the framework. The trajectory frame will allow the researcher to focus on the dynamics of spousal caregiving of older patients over time in the context of heart failure, focusing on the types of work involved. The analysis of caregiving through a trajectory framework will provide the best analytical approach to define the types of work manifested over the 12-14 month period of providing care to older patients in the context of heart failure. The theoretical basis for this study is further defined in Chapter 2.

**Research Question**

The overarching research question for this study is: What are the types of work experienced in long-term spousal caregiving of older patients across the illness progression of heart failure? This question is broad and open-ended in order to capture the full experience of the spousal caregiver. The content of what the caregivers relate will reflect the type of work at that point in the course of the illness. The goal was to capture the dynamic flow of the types of work across the 12-14 month progression of heart failure. This study was a secondary analysis of the longitudinal data collected in the larger Hupcey et al. study [AHA, 2006/2008 (Hupcey PI)]. The tenets of grounded theory method were utilized as the overarching methodology for this inquiry.

**Theoretical Definitions**

*Trajectory* refers not only to the physical unfolding of a disease, but to the:

“total organization of work done over the course of the disease together with the impact that the consequences of the disease and its work exert on the lives of the people involved” (Corbin & Strauss, 1988, p. 33-34).
Caregiving refers to the: “emotional and/or physical support given to a patient by a family member” (Saunders, 2003, p. 138) and “denotes care that is provided by a family member or friend rather than by a professional who is reimbursed for services” (Schulz & Sherwood, 2008, p. 23).

Work is defined as a “set of tasks performed by an individual or a couple, alone or in conjunction with others, to carry out a plan of action designed to manage one or more aspects of the illness and the lives of ill people and their partners” (Corbin & Strauss, 1988, p. 9).

**Significance of Study**

Spousal caregivers are an integral source of care for older patients with heart failure and provide significant contributions to the care of their spouse. Confounding this issue are the epidemic proportions of older adults living with heart failure and the demographic trends that indicate that the incidence of heart failure will continue to increase in the years to come, thus the needs of caregivers, who are instrumental partners in care cannot be ignored. The dynamic work of the caregiving experience in the context of heart failure is not well understood especially from the caregiver’s perspective and more so across time, although the potential risks of caregiving are well documented. The primary goal of this study is to gain a better understanding of the types of work experienced by spousal caregiving of older patients in the context of heart failure over time. Such information is essential to gain a better understanding of the various types of work experienced over a 12-14 month course of caregiving. The multidimensional risks (physical, psychological, and financial) to the caregiver are well established in the
literature (Rabow et al., 2004). But, amazingly, there were no identified studies in the literature that evaluated the spousal caregiving experience over time in the context of the unpredictable and uncertain illness progression of heart failure. Gaining a better understanding of the types of dynamic caregiving work and how this work changes over time is essential as this at risk group continues to increase. Expanding our knowledge of the types of work experienced by the caregiver may ultimately lead to better coordinated services to meet the needs of the caregiver as well as the heart failure patient. If the types of work change over the course of the heart failure illness progression then services can be tailored to the changing needs of the caregiver and patient. The study will also make a significant contribution defining the types of work involved in providing care over a 12-14 month period to a patient with heart failure.

In summary, caregivers are a valuable source of care for patients with heart failure living in the community but at a potential costs to their own health and well being (Rabow, Hauser, & Adams, 2004; Shanks-McElroy & Strobino, 2001). There is evidence to support that, although, providing spousal care to a patient with heart failure is very complex, this population may not receive the same services as other chronic illness conditions, placing the spousal caregiver at more risk for negative outcomes (Boyd, et. al., 2004; Molloy, Johnston, & Witham, 2005; Pattenden et al., 2007).

As the number of those diagnosed with heart failure continues to increase, more patient care responsibilities will be placed in the hands of a family caregiver which will most likely be the spouse. As the disease progresses, the types of work experienced across the course of heart failure are sadly understudied from the perspective of the
caregiver which further compounds the spousal caregiving experience. It is imperative to gain greater insight from the spouses’ perspective to identify the types of work involved with caregiving. This knowledge will help to illuminate the needs of the caregiver based on the types of work manifested from a longitudinal perspective. With this knowledge nursing can identify what and when specific services may be best suited for the caregiver and patient based on the various types of work manifested during 12-14 months of providing care. Nurses are obligated to assess and improve the caregiving environment for both the caregiver and patient. Having a better understanding of the complex caregiving needs and the types of work involved across the dynamic course of a chronic illness such as heart failure will improve the nurse’s ability to assess the needs of the caregiver and just as importantly the needs of heart failure patients.
Chapter 2

Literature Review

Introduction

The review of the literature begins with a discussion of three prominent theories which are relevant to the proposed research. First, symbolic interactionism (Blumer, 1969), a key underlying framework for grounded theory will be discussed. Next, the Illness Trajectory Framework (Wiener & Dodd, 1993) will be reviewed as it contains the concept of illness trajectory as well as the work involved in illness. This is followed by a major focus of the review, the theoretical framework of chronic illness management developed by Corbin and Strauss (1988) in their book “Unending Work and Care: Managing Chronic Illness at Home” which is the theoretical framework that was chosen to guide this study. Finally, the theoretical discussion is followed by a conceptual discussion of spousal caregiving, and caregiving and heart failure; concluding with a review of current life sustaining interventions in acute heart failure.

Theoretical Discussion

This extension of the larger Hupcey et al. [AHA, 2006/2008 (Hupcey PI)] study will utilize the tenets of grounded theory as the overarching methodology of this study. It is essential for the theory that guides this study to first be consistent with the principles of grounded theory and secondly guide the purpose of the study to explore the work of spousal caregiving longitudinally across a 12-14 month course of heart failure. The first theory presented is Symbolic Interactionism, as the foundation framework for grounded
theory, one would be remiss not to consider this framework as the guiding theory for the proposed study.

The second theoretical framework presented is The Illness Trajectory Framework (Wiener & Dodd, 1993). The theory was developed from a grounded theory study and is based on the illness trajectory of patients suffering from cancer. The framework includes all of the workers (family, caregivers, and patient) in the illness trajectory.

Corbin and Strauss (1988) developed a theoretical frame titled *Chronic Illness Management* which focuses on how chronic illness is managed at home by the patient and spouse and this will be the third theoretical framework presented. The theoretical framework was developed based on grounded theory methods. The central concept of the theoretical frame is the concept of trajectory and all other concepts presented in the theory revolve around the core concept. Another main concept in the framework is the concept of work and how managing an illness and accommodating the associated manifestations requires a considerable amount of work by all involved within the context of the spousal relationship.

**Symbolic Interactionism**

Symbolic interactionism provides the foundation and organizing framework for the method of grounded theory in qualitative research conducted in nursing and other social science disciplines such as psychology and sociology. While Herbert Blumer is credited with the term “symbolic interactionism” in 1937, the foundational work of this theory has its roots in a social psychologist named George Herbert Mead. According to Benzies and Allen (2001), Mead taught the precepts of symbolic interactionism at the University of Chicago for nearly 40 years, yet he never published a book on the topic.
After Mead’s death in 1931, his lecture notes were found and converted into a theory that was later published by Blumer in 1969.

In brief, symbolic interactionism is an approach to interpreting the actions of human beings in response to one another, based upon the meaning that is attached to actions, as actions are mediated through the use of symbols (Blumer, 1969). It was Blumer, a former student of Mead’s, who first applied symbolic interactionism to sociological theory and considered it as a research approach (Jeon, 2004).

The major concepts of symbolic interactionism center on the human attribute of “self” and how self is developed, conceptualized and reconceptualized through social interaction (Blumer, 1969). Meaning is derived as one becomes an object of his or her own action. Therefore, the self cannot be considered in isolation because the self is constantly evolving and not fixed. Mead defined self as the subjective “I” which is the spontaneous and natural self which is not hampered by others and the objective “me” which sees self as a reflection of what others see and of what one sees when looking back at oneself (Blumer, 1969). According to Jeon (2004), as one has capacity to reflect upon the self through the “I” and “me” constantly communicating with each other, human beings develop a concept of a social self. A person’s actions are a result of these inner conversations and reflections.

Building upon Mead’s work, the three major assumptions of symbolic interactionism are as follows: 1) human beings act toward things and people according to the meaning that things and people hold for them, 2) meaning is derived from social interaction, 3) people modify the meanings of things through an interpretative process as they respond to things that are encountered in the human experience (Benzies & Allen,
The first assumption is that human beings act toward things on the basis of the meanings that the things have for them. “Things” refer to physical objects, other human beings, institutions, guiding ideals, activities, and situations (Blumer, 1969).

In the second assumption, meaning arises from the process of social interaction between human beings. In symbolic interactionism, meaning is viewed as social products or creations that are formed by people as they interact (Blumer, 1969). How people act, therefore, defines the “thing” for that person, and therefore gives it meaning.

In the third assumption, meaning is further modified through an interpretative process. This process of interpretation has two distinct steps. First the actor indicates the things towards which he or she is acting and identifies the things that have meaning. Secondly, the actor selects, regroups, and transforms meaning in light of the situation and the direction of action (Blumer, 1969).

In addition to the three major tenets described above, symbolic interactionism is grounded on six root images or basic ideas. These root images represent the way in which symbolic interactionism relates to human society and conduct. The first is the nature of human society or human group life which Blumer (1969) describes as being a fundamental principle in his theory. Because human groups and society exist in action as they engage in the multitude of activities performed in life, people must be seen in terms of action. Human society consists of these activities of its members fitting together in a complex organization.

The second root image is the nature of social interaction. This root image is recognized as a process that forms the conduct of people as they interact with each other based upon how the other person acts towards them. Actions are then adjusted based
upon the interpretation of the indications, gestures or symbols made by others. According to Blumer (1969), this formative process is not a result of pre-existing psychological factors or social organization.

The nature of objects is the third root image. Objects are the product of symbolic interactionism and may be anything that can be pointed or referred to, such as a physical object, a social object, or an abstract object. Human beings form and transform objects as they give meaning to objects through social process (Blumer, 1969).

The fourth root image, human beings as an acting organism, or as an actor, recognizes human beings having a self, and acting towards self (Blumer, 1969). Human beings engage in social interaction with self and respond through a process of self-interpretation.

The nature of human action is the fifth root image. This root image refers to the ability of the human beings to confront objects in the world and act based upon interpretation of the world.

Finally, Blumer (1969) describes the interlinkage of action as the sixth root image foundational to symbolic interactionism. The interlinkage of action refers to the joint action, or social action of a group as a result of the interlinkages of the separate acts of the individual participants. Blumer concludes that joint action has a horizontal component of the linkages between all participants and the vertical linkage that is connected to previous joint action.

The strengths of symbolic interactionism as a theoretical fit with the phenomenon of interest are two-fold. First, symbolic interactionism is regarded as the underlying theoretical framework guiding grounded theory. Secondly, there is a substantial amount
of empirical support for symbolic interactionism as the guiding framework for nursing research utilizing ground theory methods (Mok, Chan, Chan, and Yeung, 1993: Jezewski & Finnell, 1998: Marcellus, 2005: Hepburn et al., 2002). As this proposed study is based on the methods of grounded theory, symbolic interactionism could be a nice theoretical fit but, the framework is lacking several essential principles to adequately guide the proposed study. First, the lack of a trajectory view of illness is a weakness as this study proposes to view the spousal caregivers of heart failure from a longitudinal perspective. Secondly, the inclusion of the patient and caregiver is not well espoused in symbolic interactionism.

**Theory of Illness Trajectory**

The concept of an illness trajectory originally stemmed from the seminal work of Glaser and Strauss (1965, 1968) and Corbin and Strauss (1988). Originating in the physical sciences, trajectory refers to the path of a projectile traveling through space (Wiener & Dodd, 1993). The path is dynamic in nature and characterized by movement through time, direction, shape, and predictability. The illness trajectory refers not only to the physical aspects of a disease, but to the “total organization of work done over the course of the disease” (Wiener & Dodd, 1993, p. 20).

These works examined the effects of patients, staff, and structure on the management of terminally ill patients. The context of the work is based on cancer patients receiving chemotherapy. The term “work” stems from earlier research in which the role of the patient as the central worker was highlighted (Fagerhaugh, Strauss, Suczek & Weiner, 1987). It also relates to the relationship among the workers that has an impact on both the management of the illness as well as the fate of the person who is ill.
The major theoretical assertions of the illness trajectory are based on the work of Corbin and Strauss (1988) which focuses on the social context for work and on the social relationships affecting the work. In this framework, illness is situated in a biographical context. According to Corbin and Strauss (1988), patients and families never spoke of just the illness but instead addressed what was going on before the illness as well as the impact of the illness on future hopes and dreams. Similar to the theoretical tenets in symbolic interactionism, interactions with others are a key influence to establishing a conception of self.

According to Wiener and Dodd (1993), the key elements of this biographical context are three conceptions of self (past, present and future) over the course of time that arise from the body. An illness interjects instability impacting the fine adjustment of the three elements. The person in the present is not the same as he or she was in the past and there is uncertainty for the self in the future. “Who I was in the past and hoped to be in the future are rendered discontinuous with who I am of the present. New conceptions of who and what I am- past, present, and future- must arise out of what remains” (Corbin & Strauss, 1988, p.10).

The first theoretical assertion of the Theory of Illness Trajectory is described as the uncertain temporality (Wiener and Dodd, 1993). This assertion is based on the influential work of Mead (1934) who explained that the future is part of the present when an individual is making a choice of action. This choice of present behavior is framed in the context of future consequences and is rooted on the recall of past experiences.

Wiener and Dodd (1993) also describe other dimensions of the uncertain temporality with
terms such as duration, pace and frequency. All of these dimensions are very dynamic in nature as the illness impacts everyday life.

The second theoretical assumption involves the uncertain body. According to Wiener and Dodd (1993), the three elements of body failure focus on the body’s ability to perform an activity, the body’s appearance, and the physiologically functioning. The uncertain body is intertwined with temporality as well. Many patients frame present bodily concerns with comparisons to the past. Future time concerns related to body failure focus on the efficacy of treatment as well as recurrence of the disease.

The third theoretical tenet espoused by Wiener and Dodd (1993) is the uncertain identity defined as: the conceptions of self from multiple aspects which at any given point in time are situated in the body. The aspects of time and a failed body also have direct influences on conceptions of self. Key to the illness trajectory is the temporary, uncertain, and dynamic nature of the chronically ill person.

The activities of life and living with a chronic illness are forms of work that involve the total organization of workers. In the illness trajectory, the ill patient is the central worker but all work is influenced by the total organization including the family and health professionals. Wiener and Dodd (1993) identify four types of trajectory work performed by the total organization these are illness related work, everyday life work, biographical work, and uncertainty abatement work.

The first line of work is illness related. Illness related work contains regimen work, symptom management and diagnostics. Everyday life work is the second line of work and includes activities of daily living, maintaining personal relationships, occupational work, and recreation. Biographical work is associated with each type of
work and includes the exchange of information, emotional expression, and the division of labor throughout the total organization. The final line of work is uncertainty abatement work. This work involves activities enacted to lessen the impact from the uncertain identity, body, and time.

The balance of the four types of work is very dynamic across time, situations, perceptions, and various workers in the total organization in order to regain some sense of balance or control. According to Wiener and Dodd (1993) there is constant tension between the lines of work that is marked by shifts in the dominant type of work displayed by the workers across the trajectory.

Wiener and Dodd (1993) also identified strategies related to uncertainty abatement work. The strategies were very dynamic and occurred in various combinations across the trajectory and for different workers in the total organization. Nine strategies were delineated in the illness trajectory. The first was pacing which involved identifying limits and successfully informing others in the organization of the changed limits. The second strategy involved becoming a professional patient. This strategy encompassed using and understanding medical terminology as well as directing care. There was also an effort to achieve a balance between expertise and supermedicalization. The third strategy was seeking a reinforcing comparison. The patients and families looked for a worse case as reassurance of their own condition. Engaging in reviews comprised the fourth strategy. This involved looking back with the workers of the organization to reexamine and reinterpret emergent symptoms and interactions within the organization. The fifth strategy of setting goals was future oriented and involved looking ahead to desired activities. The sixth strategy was identified as covering up. This strategy involved hiding
emotions and symptoms and toughing it out in front of families and friends. Finding a safe place to let down was strategy seven. This strategy was an extension of covering up and focused on identifying a safe place to express true emotions. The next strategy of choosing a supportive network is related to finding a safe place to let down your emotions. The sharing of information was a selective process by the patient and family. The final strategy was taking charge which involved the patient displaying control behaviors in the course of the treatment.

The only empirical work utilizing the illness trajectory as the underlying framework was completed by Jablonski (2004). Jablonski (2004) built a model of the end stage renal disease trajectory based on a review of the literature. The illness trajectory was then extended to end stage renal dialysis patients.

The illness trajectory is congruent with the investigator’s world-view of the phenomenon of interest in regard to the trajectory analysis of an illness and the inclusion of all of the workers in the illness as well as the various types of work performed across the trajectory. A strength of the theory is its philosophical roots emanating from the work of Corbin and Strauss (1988) and the earlier work of Blumer (1969), whose theory of symbolic interactionism is regarded as the underlying framework of grounded theory.

The theory of illness trajectory does not specifically address the theoretical components of nursing, person, health and environment, but these components are implicitly addressed in the theoretical assumptions. The theory also includes a dynamic trajectory framework which is an advantage over symbolic interactionism for the purposes of this study. The major disadvantage to utilizing the theory was the fact that it was based on a specific illness trajectory of cancer patients receiving chemotherapy.
Another limitation was the focus on the patient. The definition of work includes all players in an illness but the trajectory focused mainly on the work of the patient.

**Corbin and Strauss Chronic Illness Management**

Corbin and Strauss (1988) developed the original theory from which Illness Trajectory was developed. In order to address the issues identified above with the Illness Trajectory, in terms of the cancer context and main focus on the patient, but still maintain the trajectory focus, the original theory was reviewed to determine if it fit the phenomenon of interest.

In this grounded theory study Corbin and Strauss (1988) examined how chronic illness is managed at home, the impact of that management and the illness upon the patient and spouse, and how their domestic adjustments to the illness, in turn, affect its management. The authors present an overall theoretical frame that is grounded in their research consistent with the tenets espoused in symbolic interactionism. The central concept of the framework is “trajectory” which is based on a sociological perspective. Trajectory includes both the temporal physiological course of a disease as well as the equally important temporal sociological phenomenon of the work and work relationships that are inherent in dealing with the course of the disease. In conjunction with the unfolding trajectory of the disease are biographical consequences which in turn can impact the trajectory work of the illness itself (Corbin & Strauss, 1988). The authors define biological consequences as body, self, and sense of biographical time, the latter of which is continually being reframed throughout the illness trajectory. According to the authors this continual recontextualization involves a great deal of a particular type of work which is referred to as “biographical work.”
Corbin and Strauss (1988) address the needs of the spouse in this framework as well. The authors refer to the impact of dealing with a chronically ill spouse as “accommodation” or the day-to-day struggle of spouses to keep some kind of balance as they try to manage a chronic illness. This constant struggle involves juggling of time, space, energy, finances, employment, and activities. The complex management and accommodations required by a chronic illness are referred to as “work.” Work is defined within the framework as a set of tasks performed by an individual or a couple, alone or in conjunction with others, to carry out a plan of action designed to manage one or more aspects of the illness and the lives of ill people and their partners (Corbin & Strauss, 1988). The focus of work in the framework is threefold according to the authors. First, it allows one to differentiate the many types of work required to manage an illness within the context of the couples’ lives and then break the work down into the various tasks associated with that specific type of work. Secondly, the work focus also highlights how the tasks change in the illness trajectory and how those changes impact the management of the illness. Finally, when referring to illness management, families use the language of work, therefore, work and its associated tasks is deeply rooted in the data.

Corbin and Strauss (1988) also identify the types of work and associated tasks of the patient and spouse that are involved in managing a chronic illness. The types of work identified are illness related work, biographical work, everyday life work, and articulation work. Illness related work includes the types of tasks for controlling symptoms; monitoring, preventing, and managing crises; carrying out regimens; and managing limitations of activities. Illness related work takes place within the context of everyday life work which requires at times a complex division of labor providing a very dynamic
process. Biographical work is the work involved in defining and maintaining an identity which includes contextualizing the illness into one’s biography (making it part of everyday life) and restricting new conceptions of the self in light of the illness and bodily changes (Corbin & Strauss, 1988).

Everyday life work includes occupational work and the tasks associated with obtaining and maintaining a paid position; martial work and the tasks involved in maintaining a marriage; domestic work and the tasks associated with running a household; and child care work including the tasks associated with raising children. Corbin and Strauss (1988) also identify as a part of everyday life work the handling of social situations by the ill person and spouse as well as information work which includes the quest for, the receiving of, and the passing of information. According to Corbin and Strauss (1988), illness related work, biographical and everyday life work are all linked and reciprocally interactive.

The highest order of work is termed articulation work. Articulation work is the organization and coordination of the varied types of work that are necessary to operationalize any plan of action including not only the illness related work but everyday life work. Articulation requires identifying the types of work and associated tasks that need to be done and prioritizing the work and tasks.

The work associated with managing a chronic illness is a dynamic process and the term given for the complex trajectory management process is “structure in process” Structure in process means that there are changes and fluctuations in the course of the illness, everyday life and biography, each reciprocally impacting the management of the other type of work.
The work associated with the management of a chronic illness is very active and dynamic and is rooted in a sociological perspective, although the illness itself is physiologically based. The two perspectives are merged with the central concept of the theoretical frame of “trajectory.” According to Corbin and Strauss (1988) trajectory refers “not only to the physical unfolding of a disease but to the total organization of work done over the course of the illness plus the impact on those involved with that work and its organization” (Corbin & Strauss, 1988, p. 33-34). The concept of trajectory is designed to focus us on the active role that people play in shaping the course of an illness. Trajectories have two important properties variability and phasing. Trajectories are variable not only in form but also in the duration of the work to be done. The phasing of the trajectory gives the trajectory its shape and corresponds to the physical and physiological status of the illness. According to Corbin and Strauss (1988) phasing has an analytical significance because it denotes the type of work to be done and the potential impact of that work. The phases of the illness trajectory are identified as: acute, comeback, stable, unstable and downward.

The trajectory is shaped and influenced by the actions not only of the patient but all of the workers involved such as the spouse, healthcare workers, and families. Ultimately, the couple is primarily involved in carrying out the day-to-day work involved in chronic illness management, resolving the issues and problems related to that work and in the end who are most affected by the consequences of the illness and illness related work. The central concept of trajectory is used to order and organize all of the work related action that takes place in the interaction of work performance. The authors provide a conditional matrix (Figure 2.1) to illustrate the interactional system involved in
the work performance of managing a chronic illness. Because the framework is interactional in nature, the flow of the work processes transition from one phase to the next. The interactional matrix has four essential characteristics. First it is made up of interrelated levels, each level represents a set of conditions. Second, the matrix moves both inward toward the center and outward away from the center. The third characteristic of the matrix is that each level feeds into the next as it moves inward and outward. Finally, the consequences from action may come back and impact on the current conditions either to maintain or change those conditions (Corbin & Strauss, 1988).

Corbin and Strauss (1988) stress that the dynamic nature of an illness trajectory is difficult to convey in a single diagram and the conditional matrix is just one phase or cross-sectional slice of the total interaction. The matrix represents an action scheme that represents the conditions, work related actions and interactions, and the consequences involved in work performance that are involved in the couple’s life that is complicated by a chronic illness. The outer circle represents macro conditions such as health related legislation, medical technology as well as the number of resources available in the couple’s community. The next circle of illness, biography and everyday life combine to create the management of the illness trajectory. Work is the next circle of the matrix which can be broken down into the three major lines of work and associated tasks. This work must be identified and performed by the spouse if each line of work is to be managed. The next circle represents the structural context which according to Corbin and Strauss (1988) includes the attempts to maintain control over the trajectory, biography and everyday life. At the next level, interaction enters the matrix as work processes cannot be accomplished without some degree of self interaction or interaction with one’s
partner. Work performance is represented by the center circle. The arrows represent the flow from work performance and consequences that arise from whether or not and how the work takes place. The arrows bounce back through the various levels of the matrix to affect each level in varying degrees.

2.1 Conditional Matrix: Transactional System Between Spouses (Corbin & Strauss, 1988).

The chronic illness trajectory developed by Corbin and Strauss (1988) is very consistent with the world view of the researcher and it most adequately captures the totality of the phenomenon of interest of all the theories reviewed. Key characteristics included in this theoretical framework that are essential to frame this research are: a trajectory view of illness management that is dynamic in nature, the inclusion of the work and work processes involved in managing a chronic illness, a trajectory approach that is
not limited to the context of one specific illness, and finally the inclusion of the patient and partner as comanagers of chronic illness. Further, the framework is theoretically congruent with the nursing process because the researchers specifically address the concepts of person, health, environment and nursing as part of the conceptual model.

There is also empirical evidence supporting the conceptual model. The model was operationalized to elderly clients with chronic illness (Robinson et al., 1993), and those with cardiac illness (Hawthorne, 1991).

In summary, the dynamic nature of the spousal caregiving experience is most effectively framed by a trajectory framework. Three theories were presented to frame the study. Symbolic interactionism (Blumer, 1969) is the foundation of grounded theory and adequately captures the dynamic nature of the caregiving experience. Although symbolic interactionism has substantial empirical support, it lacks the trajectory approach which is essential as a theoretical underpinning for this study in order to adequately capture the phenomenon of interest.

The Theory of Illness Trajectory (Wiener & Dodd, 1993) includes all of the workers in the illness trajectory (i.e. family, caregivers, and patient) which is a key component of the research question. The key tenets of grounded theory, illness trajectory, and most importantly the work assumed by the patient and family throughout the course of the disease are all addressed by the theory. The main limitation of the theory is the focus on the specific trajectory of cancer which may limit the generalizability of the theory. Another concern with the theory is the role of the caregiver is included but the main focus remains on the work of the patient.
The illness trajectory framework by Corbin and Strauss (1988) has the strongest theoretical fit with the phenomenon of interest and captures the dynamic nature of an illness over time encompassing a multidimensional perspective including both the patient and spouse. Inclusion of the patient and spousal caregiver as a theoretical tenet is essential to maintain congruence with the researcher’s worldview of the phenomenon. The key principles of grounded theory, illness trajectory, the caregiver and patient, and most importantly the work assumed by the patient and family throughout the course of the disease are all addressed by the theory which is the main reason the illness trajectory framework was selected as the guiding theory for this proposed study.

**Conceptual Discussion**

**Spousal Caregiving and Chronic Illness**

The purpose of this study is to explore the work of spousal caregiving across the illness progression of heart failure. The databases for the literature review were Cumulative Index for Nursing and Allied Health Literature (CINAHL), PubMed, and PsycINFO. The literature searches used caregiver and spouse, caregiver and trajectory, caregiver and transition, and caregiver and heart failure as the key words. Each database was searched with the same series of key words. The reference lists of articles retrieved from the database search were also reviewed for pertinent literature. A review was also conducted to identify the most current treatments and devices in regards to heart failure management. New treatments and devices have increased the longevity of patients with heart failure and may have an impact on the caregiving experience and similarly the caregiving trajectory.
It is increasingly recognized that chronic illness not only impacts the life of the patient but also has profound implications for those who live with the chronically ill patient, in particular the spouse (Baanders & Heijmans, 2007). In our current health care culture, there is increasing focus on home-based health care for the chronically ill. The spouses are often expected to provide the home care necessary for the chronically ill patient (Shaw et al., 1997). The diagnosis of a chronic illness brings with it physical and emotional alterations together with fear and uncertainty regarding the future (Erikson & Svedlund, 2006).

One of the most consistent findings in the caregiver literature is that the majority of informal caregivers are spousal women providing care in the home setting. According to Aneshensel and colleagues (1995), unlike most careers, caregiving is unplanned, unexpected, and not entered into by choice. Rather, family members are drawn into caregiving insidiously often functioning as caregivers even before they see themselves as caregivers. One factor that impacts the subjective role transition into the caregiving role is whether the onset of the need for care is abrupt or gradual. According to Seltzer and Li (2000) very little past research has examined this transition into the caregiving process. A study conducted by Reese (2003) contrasted caregivers of persons with Alzheimer’s disease (gradual onset) with caregivers of persons who had suffered a stroke (sudden onset.) The objective duration of caregiving (i.e., years since diagnosis) was consistent for both samples. However, the researcher found that caregivers of persons with Alzheimer’s disease were more distressed psychologically than caregivers of persons with stroke. The author concluded that caregivers of persons with Alzheimer’s disease
probably unknown to themselves, had been caregivers for years prior to the date that they identified as the onset of their caregiving experience.

The caregiving role is experienced very differently among caregivers. Some studies found that the longer the duration of care, the poorer the caregiver well being (Skaff, Pearlin, & Mullan, 1996). In contrast, others found that over time some caregivers develop new coping skills (Zarit, Todd, & Zarit, 1986). These two patterns reflect competing explanations of the over time impact of caregiving: the wear and tear hypothesis versus the adaptation hypothesis (Townsend & Franks, 1997).

In the past, researchers have focused on the needs of the care recipient. Little attention was given to understanding the role of the caregiver. Currently, there is an emerging body of literature focused on the role of the spousal caregiver (Cheung & Hocking, 2004; Coombs, 2007; Stodberg, Sunvisson, & Ahlstrom, 2007). Studies indicate that caregiving may affect the physical, mental, and social health of the caregiver (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Son et al., 2007). There are many aspects of assuming the role of the caregiver, Dillehay and Sandys (1990) broadly categorized these adjustments into physical, psychological, financial and social health. These broad categorizations will frame the conceptual overview of caregiving. Following this review, caregiving issues specific to heart failure will be reviewed.

**The Physical Impact of Caregiving**

The stress associated with the caregiving role can adversely impact the caregiver’s health (Lieberman & Fischer, 1995). In a study by Teel and Press (1999), 92 spousal caregivers who cared for a patient with cancer, dementia, or Parkinson’s Disease were compared to a noncaregiver control group (n=33) for fatigue, energy, sleep, and
self-reported measure of health. Caregivers reported fatigue levels that were significantly greater ($p < .05$) than those of the control group. The researchers also found that self-reported health was poorer among caregivers of patients diagnosed with dementia than among age matched peers not in the caring role. Only one-half of caregivers reported their health as good or excellent, as opposed to three fourths of their peers in a non caregiving role. All three groups of caregivers reported higher levels of sleep disturbance and lower levels of sleep effectiveness than noncaregivers. Thompson and Cordle (1988) found that 77% of the wives they studied ($n=76$) experienced fatigue and insomnia, 25% had palpitations, and 18% had consulted their physician for new physical symptoms that had emerged since their husband’s myocardial infarction. In a study by Navaie-Waliser and colleagues, (2002) over one-third of the informal carers in the study ($n=1002$) reported their physical health had suffered since becoming a caregiver. The effects of caregiving on physical health include that caregiving can lead to slower wound healing (Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1995), increased blood pressure and cardiovascular disease, as well as altered lipid profiles (King, Oka, & Young, 1994). Hirst (2005) demonstrated that a demanding caregiving role (i.e. providing assistance with basic ADLs for 20 hours or more per week) resulted in increased depression and psychological distress, impaired self-care, and poorer self-reported health.

It is also important to take into the consideration the underlying health status of the caregivers. Chronic illness increases with age and most patients with heart failure are 65 years or older (AHA, 2010). Therefore caregivers of chronically ill individuals are most likely in a similar age range and may have baseline underlying health issues as well which may be exacerbated by assuming the caregiving role. The physical and
A meta-analysis by Vitaliano, Zhang, and Scanlan (2003) combined the results of 23 studies to compare the physical health of caregivers with demographically similar noncaregivers. Caregivers had a 23% higher level of stress hormones and a 15% lower level of antibody response than did noncaregivers. The authors stress the findings in the study cannot be inferred as cause and effect due to the study design but the findings do have profound implications for caregivers.

The role of caregiving may also impact the health behaviors of the caregiver. Health behaviors refer to the self care behaviors utilized by caregivers to promote their own health and well being. The caregiving role may be a 24-hour a day responsibility that requires hands on assistance as well as juggling the multiple doctor’s appointments and frequent hospitalizations. The busy caregiving schedule may result in the caregiver neglecting his or her own self care, through sleeping less, eating too much or too little, and not exercising (Schulz et al., 1997). The caregiver’s neglect of his or her own health may worsen preexisting illnesses or increase risk and vulnerabilities for new problems.

Shaw et al. (1997) longitudinally evaluated 150 spousal caregivers of Alzheimer’s disease and 46 married control participants by a Cox proportional hazards model to test the hypothesis that spousal caregivers experience an accelerated rate of health decline relative to controls. Although no statistically significant group differences were found between caregivers and controls, the authors identified health decline to be significantly accelerated by greater ADL responsibility. Another interesting finding of this study was reluctance among caregivers to schedule hospital care for themselves at times when the psychological impact of caregiving in the older adult will be reviewed in a separate section below.
spouse appeared to have the greatest caregiving needs. If caregivers are reluctant to self-admit for needed care this practice could have serious long term consequences for the caregiver’s physical health.

In contrast to the above research, Son et al. (2007) interviewed 234 primary caregivers of dementia patients. A positive relation was found between higher stress and greater health service use, as well as stress and poorer self reported health, and negative health behaviors reported by the caregivers. An identified limitation of this study was the lack of a control group. The study was also cross-sectional in design with only one data point or interview conducted with the caregivers. Although, this study is in contrast to the findings of Shaw et al. (1997), both studies highlight the potential vulnerabilities of caregiving.

Given the impact of health changes on the caregiver, it is not surprising that caregivers have a greater risk of mortality, than noncaregivers. In a landmark 4-year longitudinal study, Schulz and Beach (1999) found that people who were providing care for a spouse and experiencing strain had mortality risks that were 63% higher than those whose spouse was not disabled. This influential work highlights the urgent need to understand the experiences of the caregiver and the impact of the caregiving role on physical health.

The Psychological Impact of Caregiving

One of the most frequently reported mental health symptoms related to caregiving is depression. In a study of 101 patients with advanced cancer and their spousal caregivers, the spousal caregivers were identified as being at high risk for depression and
over one-third of the caregivers reported significant symptoms for depression compared to only 20% of the care recipients (Braun et al., 2007).

Similarities of the detrimental impact of spousal illness on the caregiver have been demonstrated in other psychological domains as well. Emrick-Herring (1985) suggested that spousal caregivers need as much guidance and counseling as the patient for adapting to the changing lifestyle of chronic illness. Some authors have suggested that the level of distress for a wife caregiver may equal or even exceed that of her chronically ill husband (Gillis & Neuhaus, 1990).

The risk for depression was not limited to carers of cancer patients. Draper and Brocklehurst (2007), evaluated stroke patients and their spousal caregivers (n= 44 couples) and found a greater degree of psychiatric morbidity in spousal caregivers of stroke survivors as compared to a reference group. The level of psychiatric morbidity was not found to be directly proportional to the patient’s functional disability. The mental health impact of caregiving is not limited to depression. Psychological symptoms such as anxiety (Christensen & Anderson, 1989), tension, worry (Cheung & Hocking, 2004), and perception of loss of control, helplessness, and fear for the future (Martennson, Dracup, Canary, & Fridlund, 2003) are evident in the literature.

Recently researchers have focused not only on the provision of care as the cause of the caregiver distress, but also on the caregiver’s perception of how much the patient is suffering. According to Schulz et al. (2008), patient suffering is manifested in three ways: overt physical signs, including verbal and nonverbal expressions of pain and physical discomfort, such as difficulty breathing; psychological symptoms of distress, such as depression; and lack of spiritual well-being, reflecting the extent to which beliefs
provide strength. The authors found that psychological and spiritual patient suffering were significantly associated with caregiver depression and use of antidepressant medications.

**The Financial Consequences of Caregiving**

The financial issues of caring for a chronically ill person are multifaceted. Upon the diagnosis and progression through a chronic illness, the patient may no longer be able to work due to impaired functional capacity. The impact to the caregiver is varied. A previously non-working spouse may need to return to work to financially support the household or a previously working spouse may need to stop working to provide care (Covinsky, Goldman, & Cook, 1994).

In a study by Jo and colleagues (2007), ten spousal caregivers and care recipient dyads were interviewed. Caregivers described many negative reactions to caregiving such as financial strain and lack of time related to the role. Caregivers noted that the costs of medical equipment and drugs were considerable expenses. One caregiver in the study reported, “the cost of getting sick is enough to make you sick” (Jo, Brazil, Lohfeld, & Willison, 2007, pg. 14). In some cases a loss of medical benefits was experienced which is an essential resource in times of a chronic illness. Covinsky et al. (1994) examined the impact of illness on the families of seriously ill adults and the economic impact (n= 2661). The researchers found that loss of most or all of the family savings was reported by 31% of families, and in 20% of the cases, a family member had to quit work or make other major life changes to provide care for the patient.

Stone, Cafferata, and Sangel (1987) reported from the National Long-Term Survey on Informal Caregiving that there were significant conflicts between employment
and caregivers. Twenty percent reported the need to alter their work schedules, 20% cut back on work hours, 20% rearranged their schedules, and 19% took time off without pay. In order to lessen this financial burden, a large number of caregivers try to simultaneously work outside the home while providing care at home. This double duty has resulted in increased reports of stress (McLean, Roper-Hall, Mayer, & Main, 1991), lack of free time, feelings of extreme tiredness, and perceptions of being “worn-out” (McGarry & Arthur, 2001).

The literature related to spousal caregiving and chronic illness is multidimensional. The process of caregiving has a profound impact on all aspects of the caregiver’s life. It is critical to note that the majority of the literature reviewed above is cross-sectional in nature. Cross-sectional studies provide valuable insights on the process of caregiving but these insights are mere snapshots in time. The process of caregiving and especially the process of caregiving in heart failure is a dynamic process, which cross-sectional research does not clearly illuminate.

The Social Consequences of Caregiving

The social consequences of caregiving are also complex. Caregivers often experience social isolation and lack time for self, family and friends. Career interruptions may also effect the caregiver’s social life (Robinson, 1990).

George and Gwyther (1986), included a number of social activities of the caregiver as one of their dimensions of well being, these activities included: phone contacts and visits with family and friends; church attendance; club attendance; hobbies; and relaxation. Satisfaction with social activities was also assessed. When each of the
dimensions was compared with normative data, the caregivers were less socially involved than the comparison group.

Loss and social isolation are mentioned consistently as ongoing problems facing caregivers (Dewis & Niskala, 1992). Browning and Schwirian (1994) found that friends of caregivers distance themselves to avoid having to envision losing their own spouses, thus increasing the social isolation. Given, Stommel, Collins, and King (1990) reported family functioning worsens mildly over time as caregivers continue to experience family adjustments. The longer care is provided, the more likely family functioning will decline and other family members may withdraw from the demands of caregiving, leaving the caregiver feeling abandoned by the family (Given et al., 1990). Seltzer and Li (2000) completed a prospective study which examined 3 types of caregiving transitions experienced by wives and daughters: entry, institutionalization, and bereavement. After becoming a caregiver, wives experienced decreases in their participation in leisure activities, perceptions of quality of family relations, and degree of marital satisfaction. Of note, none of the wives in this study institutionalized their husband, as compared to 10% of the daughters.

**The Positive Aspects of Caregiving**

The majority of the conceptual review focused on the negative outcomes of caregiving. The review would be remiss not to include the positive aspects of caregiving. In a study by Schulz et al. (1997), about 80% of persons living with a spouse with a disability provided care to their spouse but only one-half of caregivers reported strain or negative health effects. This finding was supported by the findings from the first 2 waves of the Caregiver Health Effect Study (Beach, Schulz, Yee, & Jackson, 2000). The
researchers found in the study of 680 caregivers, increases in care were related to decreases in anxiety and depression.

The Physical Impact of Caregiving on the Older Adult

About one half of primary caregivers and one third of all family caregivers are spouses, and of these, 80% are older than 65 years of age (Stone, Cafferata, & Sangl, 1987). Thus, the older adult caregiver constitutes an especially important and vulnerable subset of caregivers. The emotional strain and the physical demands of caregiving are superimposed on the stresses the older adult is already experiencing as they attempt to cope with their own aging and all of the associated changes (Crossman, London, & Barry, 1981). The vulnerabilities of older adult caregivers were probably most aptly summarized by Fengler and Goodrich (1979) when they were referred to as “the hidden patients.”

In a meta-analysis on the physical impact of caregiving to dementia patients the researcher’s quantified relationships of caregiving with health problems (Vitaliano, Zhange, & Scanlan, 2003). The authors concluded of the 23 studies included in the analysis, caregivers exhibited a slightly greater risk for health problems than noncaregivers. More importantly, many methodological limitations were identified in the literature included in the meta-analysis such as the use self-reported health (as opposed to physiologic data), lack of a comparison group, and retrospective or cross-sectional designs. Although this study was not limited to the older caregiver, the researchers noted that older caregivers, especially those with comorbidities, have been “essentially ignored” in this literature highlighting the urgent need for further study in this vulnerable group.
Navaie-Wallis et al. (2002) examined the characteristics, activities and challenges of high-risk informal caregivers (n=1002). The vulnerable caregivers (those who reported being in fair to poor health or having a serious health condition) were compared to the non-vulnerable (caregivers without the above characteristic). Although the sample was not exclusively elderly, 36% of the caregivers surveyed were identified as vulnerable and were at least 65 years of age. Vulnerable caregivers were more likely to experience difficulties with providing care, to have unmet needs in providing care, to report their physical health had suffered since becoming a caregiver, and were no more likely than non-vulnerable caregivers to have received help or support for their care recipients. About one-half were providing care for 20 or more hours per week and vulnerable caregivers were more likely to be providing high intensity care. This study was one of the few reviewed that stratified caregivers into vulnerable and non-vulnerable groups for comparison. The sample was also a national representative cross section of households. The study did not however report the health status or condition of the care recipient.

Wallsten (2000) sought to determine whether the findings regarding psychological health are reflected in the physical burden of care through a cross-sectional analysis of a longitudinal study of 234 older couples (118 caregiving and 116 comparisons). The findings of the study suggest that the chronic, ongoing nature of caregiving produces negative effects on the caregiver’s health symptoms and ability to carry out activities of daily living. The study had one of the most representative samples of the studies reviewed but it should be noted that physical symptoms were self reported
and the findings were from a cross-sectional analysis which would limit causal statements.

Key to successful aging is the adoption of preventive health behaviors such as exercising, healthy eating, maintaining a healthy weight, getting adequate sleep, not smoking, and not abusing alcohol. In a study by Gallant and Connell (1997), the health behaviors of a sample (n=233) of older adult spouse caregivers was evaluated for decreased self-care behaviors increasing the risk for adverse health outcomes. The researcher found that negative health behavior change was significantly associated with lower levels of self-efficacy for both self and spouse. Negative health behavior change was associated with a longer duration of caregiving, more on-duty hours, and a greater number of ADL tasks. Finally, negative health behavior change was also associated with less social support, higher levels of burden, and higher levels of depression. Similar to the majority of studies reviewed, the data was based on self-reported measures, the design was cross-sectional, and most importantly there was a lack of a comparison group.

The Psychological Impact of Caregiving on the Older Adult

The mental health effects of caregiving most commonly reported in the literature include the domains of: depression, anxiety, stress, subjective well-being, and self efficacy (Schulz & Sherwood, 2008). Given et al. (1990) identified three categories of variables to predict spouses’ reactions to caregiving roles. The categories included were: patient characteristics, the caregiving environment, and characteristics of the caregiver in a sample of 159 spouse caregivers (mean age 69). The care recipients had a wide variety of chronic illnesses and were perceived by the caregiver to be in poor health. In terms of patient characteristics, cognitive impairments and negative behaviors appeared to make
significant and independent contributions to explaining spouse caregivers’ negative response to caregiving and their feelings of responsibility. In terms of the caregiving environment the hours of care and extent of involvement with tasks were not significantly correlated with a negative caregiver response. Negative spouse responses were significant in the domain of “impact on daily schedule” as well as “feelings of abandonment”. The strength of this inquiry was the use of the multidimensional approach, the size of the sample, and the variety of chronic conditions in the care recipients.

Wallhagen (1992) evaluated the demands (both objective and subjective) experienced by older caregivers (>60 years of age) and how those demands influenced the caregivers’ (n=60) well being as measured by life satisfaction, depression and subjective symptoms of stress. The researcher found that while some of the tasks (e.g. toileting and medications) associated with caregiving were difficult, the caregivers identified the personal demands as most taxing. The study participants noted that the care recipients were always on their minds and they could not get a mental break even if they could get a physical break. In addition, communication was changed so that many of the caregivers no longer had their spouses to turn to for support. It was also evident that the subjective aspects of caring were the aspects of caregiving that most directly impacted the caregivers’ reports of life satisfaction and depression. A limitation of the study is the lack of a comparable control group. A strength of the study is the inclusion of care recipients with a variety of chronic illnesses including both physical and mental impairments.
**Caregiving and Heart Failure**

Successfully managing heart failure has implications for both the patient and caregiver. Management of heart failure requires patients and caregivers to incorporate complex medical regimens into their daily routines and adopt very stringent dietary changes in terms of sodium and fluid restrictions that may conflict with normal routines. Both patients and caregivers must be astute in the recognition of sometimes subtle symptoms of heart failure to prevent deterioration in status that may require hospitalization. Finally, patients and families must learn to adapt with impairments in physical functioning as well as to the psychological burden of living with new limitations (Dracup et al., 2004).

The unpredictable illness course of heart failure compounds the challenges to successful management. Although the disease course progresses over time, there are distinct acute and chronic phases to the disease process that interject instability and uncertainty for both the patient and caregiver. In addition to the unstable disease course and perhaps of greater significance is the increased risk of sudden cardiac death in patients with heart failure (AHA, 2010). It is estimated that up to 50% of people with heart failure die suddenly (AHA, 2010).

There is a growing body of literature related to the caregiving experience in the context of heart failure. Consistent with the caregiving literature reviewed above, the majority of the literature is cross-sectional in nature revealing findings related to one point in time in relation to the caregiving role. The main categories of physical, psychological, financial and social impact of caregiving that were explored in the general caregiving review are consistent in the caregiving literature specific to heart failure. Four
key areas that were found to build upon the general review specific to heart failure literature will be explored. These areas include: professional support of heart failure patients and caregivers, social support for heart failure caregivers, caregiver burden and heart failure, and life sustaining interventions in heart failure.

**Professional Support of Heart Failure Patients and Caregivers**

The influences of the unpredictable course of heart failure were apparent in the literature. Hawthorne (1991) described this aptly as the “chronically critically ill”. Heart failure patients have prolonged intensive care unit stays because of complications or the necessity of highly technical care. Despite their reliance upon specialized care and mechanical support, recovery is often a reasonable hope for many (Hawthorne, 1991). This expectation of recovery may be due to the fact that this exact expectation had been met many times in the past. The expectation of recovery leads to a false sense of security for some and to uncertainty for others.

Highly technical care also necessitated care across multiple settings. For some caregivers, this type of care seemed to lack coordination. In a study by Boyd et al., (2004) patients and caregivers described the coordination of their care from acute care to specialized care and home as poor in terms of coordination. This finding regarding a lack of coordination of care was supported in a study by Aldred et al. (2005b). In addition to the lack of coordinated care reported by the participants, there was also reported confusion regarding their diagnosis, treatment, and prognosis. This lack of coordination also took on a different perspective for caregivers. In a study by Luttik and colleagues (2007), caregivers reported they did not feel involved or informed by healthcare providers in the care of the heart failure patient. Caregivers reported even when present
for discussions by the healthcare team, they did not feel their presence was acknowledged.

This finding was confirmed in a qualitative study by Martensson et al. (2001) that evaluated the experience of critical incidents with 23 spousal caregivers. A critical incident was defined as a positive or negative situation of great importance to the study participant. An important theme that emerged from the study was the spouse feeling like an outsider (i.e. feeling ignored, uninformed and not acknowledged as a caregiver). Spousal caregivers reported negative feelings when the health care team gave them little information regarding the care recipient. They also reported feeling in the way of patient care and feeling frustrated when the health care team would not listen to their problems regarding the patient’s care. Molloy, Johnston, and Witham (2005) reported in a review and analysis of the family caregiving and heart failure literature that research into discharge planning and support for heart failure patients proceeded for the most part with the inclusion of the informal caregivers of heart failure patients.

Family caregivers who reported more involvement in discharge planning reported significantly higher scores on satisfaction, feelings of preparedness, perceptions of care continuity, acceptance of the caregiving role, and self reported health than those who reported little or no involvement in the discharge process. These findings were reported in a prospective, longitudinal study of 130 family caregivers (Bull, Hansen, & Gross, 2000).

In summary, the findings of the above studies suggest that caregivers feel isolated in their role and perceive a lack of support from the health care team. The need for more
research that provides nurses with a better understanding of where to target interventions and provide assistance to the caregivers is greatly needed.

**Social Support for Heart Failure Caregivers**

Consistent with the perception of lack of professional support, caregivers of patients with heart failure also reported a perceived lack of social support. Aldred et al. (2005a) reported one of the most interesting findings in their study of advanced heart failure patients and their caregivers was the socially isolating impact the disease had on the couple. All participants and caregivers in the study reported they had to stay in the house for most of the time. A similar finding was reported in a qualitative study by Luttik et al. (2007). The participants of the study reported they did not talk about or seek support from neighbors or friends because of a perceived lack of understanding regarding heart failure.

Caregiving strain and quality of life questionnaires were completed by 213 heart failure caregivers every three months for 2 years as well as 16 qualitative interviews in a study by Barnes et al. (2006). The findings from the qualitative data highlighted the fact that the debilitating symptoms and poor mobility associated with heart failure, limited the social activities of the family caregivers. The caregivers reported feelings of “guilt” associated with leaving the patient unattended.

This perceived lack of social support may also be evaluated in terms of caregiver burden. The costs of caregiving are sometimes conceptualized as burden (Zarit et al., 1986). Perception of burden is very subjective in nature and the literature reflects this with multiple definitions of this concept. Consistent in several definitions (George & Gwyther, 1986; Zarit et al., 1986), it is important to consider not only the stressors
perceived by the caregiver, but also those that exist in the context of caregiving regardless of the person’s appraisal. Caregiving takes a toll on relationships even if a person does not perceive caregiving as burdensome (George & Gwyther, 1986). Predictable stressors of caregiving that may be perceived as stressful include role overload, physical demands, financial burden, emotional issues, caregiver fatigue, and uncertainty related to the potential death of a loved one (Holicky, 1996).

**Caregiver Burden and Heart Failure**

From the definitions of burden, several researchers have evaluated the link between disease severity and caregiver burden. Karmilovich (1994) conducted the first heart failure caregiver study related to burden. Karmilovich (1994) evaluated the relationship of left ventricular ejection fraction, caregiver burden, and the concept of “cardiac invalidism”. Karmilovich (1994) hypothesized that as the heart failure patient decreases activities and self care in an attempt to preserve cardiac function, the spouse would experience more caregiver strain. The research did not support a significant relationship between the two factors. It is important to note the age of the sample. The majority of caregivers were female and ranged in age from 51 to 60 years of age. Similarly, the patients ranged in age between 51 and 60. This sample is younger than a typical heart failure patient; therefore the level of caregiver burden may have been much higher in a more representative patient sample.

A similar finding was reported in a study by Luttik et al. (2007). In this qualitative study 13 spousal caregivers were interviewed. The researchers found that disease severity is not an important issue related to caregiver burden. Also the researchers did not find a relationship between co-morbidity and the amount of caregiver
burden. In this study the age range of the caregiver was from 47-70 years of age with a mean of 66 years of age. The age range of the patients was from 46-79 years of age with a mean of 68 years of age. This is a more representative sample of heart failure patients, although 12 of the 13 respondents were classified as NYHA II which indicates less severe heart failure which limits the generalizability of the results.

A differing result was found in a study by Gure, Kabeto, Blaum, and Langa (2007) in which the amount of caregiver burden was determined based on the prevalence of physical disability and coexisting geriatric conditions in the heart failure patient. The researchers concluded that heart failure poses a significant burden on families and the long term care system.

Saunders (2008) examined the association of caregiver characteristics and the caregiving environment on caregiver burden using a cross-sectional study of 50 caregivers. Significantly higher levels of burden were associated with certain caregiver characteristics such as unemployment, caring for additional person(s), and having multiple health problems. Fifty-one percent of the variance in caregiver burden was accounted for by the variables of caregiver age, caregiver hours of care, caregiver physical health problems, and patient comorbidities.

The literature to date on burden and heart failure has focused on the relationship of disease severity and caregiver burden. According to Baanders and Heijmans (2007), burden also needs to be evaluated outside the realm of physical caregiving. The researchers give an example related to the unpredictability of the patient’s condition and the anticipation of a bad day forcing the caregiver to set aside their own needs and
reorganize their life in advance. According to the researchers this direct effect on the caregiver’s life remains unobserved in the current measurement of caregiver burden.

**Life Sustaining Interventions in Acute Heart Failure**

The management of heart failure has benefited from technological advances over recent years. The two most common cardiac support devices approved by the FDA are implantable cardiac defibrillators and left ventricular assist devices. The impact these devices have on caregiving have not been clearly established to date. It is not clear from the very small body of literature what the effects on caregivers are and how caregivers will respond to and cope with supporting an individual with a device.

In a small qualitatively designed study of eight partners who cared for a loved one with an implantable cardiac defibrillator, the researchers concluded through participant interviews that partners move through adaptive stages when learning how to support the patient (Albarran, Tagney, & James, 2004). The stages begin with uncertainty and progress to increased confidence and a resumption of activities to bring normality to their lives. The partners also described feeling excluded from the discussions relating to the patient as well as difficulty in obtaining information about the patient’s condition and the device.

Casida (2005) explored via phenomenology the lived experience of three female spouses serving as caregivers of patients with a left ventricular assist device (LVAD) prior to heart transplantation. The researcher described a continuum from guilt, fear, and anxiety prior to the LVAD to a sense of optimism and a new lease on life after the LVAD was implanted. The participants described a very difficult role as caregiver with continued anxiety and caregiver burden immediately after the LVAD insertion. This
progressed into a theme of determination by the caregivers, although the study results are limited due to a small sample size (n=3).

A similar quantitative study evaluated the long term emotional consequences of LVAD implantation followed by a heart transplant (Bunzel, Laederach-Hofmann, Wieselthaler, Roethy, & Wolner, 2007). The study was cross-sectional in design and included patients and spouses. The researchers concluded that LVAD implantation followed by a heart transplant does not lead to post traumatic stress disorder in patients but it does in their spouses. The researchers found that 26% of the spouses showed symptoms of post traumatic stress disorder even many years after their partner’s illness, LVAD implantation, and heart transplantation.

Although this area of research is in its infancy due to the recent technological advances in heart failure care, the findings indicate additional issues for the spousal carers of heart failure patients. It is also clear that devices may influence the trajectory framework for illness.

Summary of the Conceptual Literature

Consistent with the caregiver and chronic illness literature, the current literature on caregiving and heart failure is cross sectional in nature providing only a one point in time snapshot into the dynamic process of caring for a spouse with heart failure. A few qualitative studies deal with the phenomenon of caregiving and heart failure. This may be due, at least in part to the changing course of heart disease. Years ago, many people died of an initial myocardial infarction and many fewer survived to develop heart failure. Improvements in care have created the current epidemic of heart failure, which is going to escalate as the population ages. This in turn will cause an increased need for spousal
caregivers and increased work related to caregiving as technically advanced life sustaining treatments are now in the home environment.

The main design of the studies reviewed was cross-sectional in nature which cannot fully capture the experience of the dynamic, unpredictable illness of heart failure over time. The few studies that were longitudinal in nature only evaluated one aspect of the caregiving process such as burden (Shaw et al., 1997; Zarit et al., 1986). The experience of caring for a patient with heart failure has both acute and chronic phases. The full experience of the work involved in caregiving cannot be fully explored without a longitudinal view capturing the fluctuating and dynamic nature of heart failure. In this extensive review of the literature no studies were identified that explored the experience of spousal caregiving across the trajectory of heart failure or comprehensively defined the work involved in caregiving. This identified gap in the current literature warrants further investigation.

**Chapter Summary**

The literature supports the conceptualization that caregiving in the context of heart failure is a dynamic process that remains poorly understood. In congruence with the worldview of the researcher, this phenomenon is best suited to a theoretical framework that encompasses all of the work involved in the care of the heart failure patient over time. This will be best accomplished by the Corbin and Strauss Chronic Illness Management theoretical framework (1988).

It is also clear from the reviewed research, that spousal caregiving is a multidimensional process of various types of work that impacts the physical, psychological, social, and financial well being of the caregiver. This complex
phenomenon is best understood by evaluating the experiences over time from the caregiver perspective. Identifying and defining the types of work experienced by the caregiver over the course of 12-14 month time frame may assist future intervention studies.
Chapter 3
Research Design and Methods

The overarching research question for this study was: What are the types of work experienced in long term spousal caregiving of older patients across the illness progression of heart failure?

The purpose of this study was to define the types of work experienced in long term spousal caregiving of older patients across the illness progression of heart failure. Caring for an older spouse with heart failure is very dynamic in nature with changes occurring over time and over the course of the illness. This complex experience is best captured through qualitative inquiry that is longitudinal in nature. The first aim of the study was to gain a deeper understanding of the types of work in spousal caregiving across the illness progression of heart failure and to define the types of work manifested in 12-14 months of caregiving to an older patient. The second aim of this study was to generate a middle range theory of the spousal caregiving in heart failure.

Original Study by Hupcey

This study was an extension of a longitudinal grounded theory study [AHA, 2006/2008 (Hupcey PI)]. The aim of the study was to identify the palliative care needs of older (≥62 year of age) care recipients with heart failure and their spousal caregivers.

Hupcey Setting

The original research was conducted in Central Pennsylvania utilizing referrals from a large tertiary medical center as well as a rural community hospital. These
hospitals were chosen in order to access a diverse pool of potential participants. The majority of the recruitment occurred from the clinics associated with the hospitals. Access to potential participants was attained through physicians and nurse practitioners who identified heart failure patients and spouses who met study criteria.

**Hupcey Participant Recruitment**

Participants in this grounded theory study were recruited using Institutional Review Board (IRB) approved flyers (Appendix A) posted in the medical facilities as well as private medical practices in the geographic area. The flyers specified how those interested in the study could contact the researcher directly. Upon making contact, those individuals who stated their interest in participating in the study were screened by the research team of the original study. Gatekeepers within the institutions or private medical practices were identified to assist with recruitment of potential participants. The potential participants were asked by the gatekeeper for permission to release their phone number to the research team. The potential participant was then contacted by a member of the research team. Upon making contact with potential participants, interested individuals were screened by the researcher to determine if they met the inclusion criteria. The inclusion criteria included:

- Being able to speak and understand English
- Married and the primary care provider for a spouse with a medical diagnosis of heart failure having progressed to the symptomatic stage of heart failure requiring hospitalization
- No evidence of psychiatric disorder or cognitive impairment that precludes insightful reflection
A specific class of heart failure based on the New York Heart Association (NYHA) classification was not identified as inclusion criteria due to the fluctuation in heart failure symptoms over the course of one year. A member of the research team verified that inclusion criteria were met and if so the couple was asked to participate in the study. If verbal agreement to participate was obtained, the consent process was described. An appointment was made with the couple to sign the consent form and conduct the first interview. If a heart failure couple met study criteria and was interested in participating in the study, a member of the research team gave a verbal description of the study and gave the participants two copies of the consent form prior to beginning of the interview. One consent form was used for the care recipient and a separate consent for the family caregiver. Full written consent was obtained with an IRB approved form (Appendix B). A member of the research team asked the couple to read the consent form, initial each page, and sign one consent form for the researcher’s records. The second copy of the consent form was given to the participants for their personal records. The researcher obtaining consent answered any questions and advised the participants they were consenting to participate in an initial face-to-face digitally recorded interview with approximately an additional eleven interviews either in person or via phone. A contact number for the Principal Investigator of the study was on the consent form for the participants to call with any questions or concerns.

**Hupcey Sample**

A total of 20 spousal dyads (heart failure care recipient and spousal caregiver) were recruited for the study. The spousal caregivers provided care to older care recipients (≥62) with heart failure. The heart failure care recipients ranged in age from
62-79, with a mean age of 70. The spousal caregivers ranged in age from 46-78 with a
mean age of 67. Fourteen of the caregivers were female and 6 were male.

Hupcey Sampling Techniques

Theoretical sampling was utilized in the original grounded theory inquiry and is
described by Glaser and Strauss (1967) as “a process of data collection for generating
theory whereby the analyst jointly collects, codes, and analyzes data” (p.45). Theoretical
sampling is purposeful in that the researcher seeks out individuals who have experiences
with the phenomena of interest so that full and rich descriptions of the phenomena and
human interactions in the setting can be elicited and analyzed (Denzin & Lincoln, 1998).
Whereas quantitative research strives to select a sample that is representative of the
population, qualitative methodology strives to select a sample that provides rich, detailed
information (Morse & Field, 1995).

This selection process serves to build the depth of information, to confirm
suspected emerging themes or concepts, or to negate such themes. The analysis of data
begins after the first interview and continues until saturation or redundancy occurs to
provide a full and rich description of the phenomenon of interest and to ensure adequacy
of the data collected (Morse & Field, 1995). Therefore, the sample evolves as necessary
to achieve the dynamic process of understanding how themes or categories of experiences
relate. Participant selection was guided by emerging concepts as the investigator sought
participants to confirm or negate the suspected emerging themes. Sampling was guided
by the initial analysis sessions and the emergence of themes. Sampling was adapted
throughout the course of the study based on the analysis session to include couples with
unique experiences and couples in which the care recipient had different interventions such as heart transplant or cardiac assistive devices.

**Hupcey Data Collection**

**Interviews**

In accordance with grounded theory methodology, the in-depth interview was the major data collection strategy utilized in the study (Glaser, 1978). In-depth interviews take place during encounters between the researcher and informants with the goal of eliciting the informants’ perspective on their lives, experiences, or situations as expressed in their own words (Glaser, 1978).

Each caregiver was interviewed approximately each month during the enrollment period. A total of 20 spousal caregivers were interviewed up to 12 times over a period of up to 14 months. All initial interviews began with descriptive information including: age, ethnicity, length of time since the care recipient’s diagnosis with heart failure, characteristics of the care recipient’s health status, and types of assistance provided by the caregiver. The semi-structured interview guide (Appendix C) for the study was designed to elicit from participants their personal perspectives on their lives, experiences, and situations as caregivers to spouses with heart failure. The use of the semi-structured interview guide served as a reference point while the researcher and participant moved back and forth during the interview process discovering events and experiences that shaped the phenomenon of interest.

The interview began with the question “Tell me about your experiences providing care to ______.” This initial interview question was designed to elicit a broad description of the experiences of caring for a spouse with heart failure. Changes as a
result of the caregiving experience were discussed. It was expected that caregivers’ responses would provide a full and rich description of the context (everyday life with heart failure), including the caregivers’ interpretations of how heart failure affects them personally. Probes included:

- Are there things that you do that the care-recipient once did?
- How has this affected your life?
- Are you able to do these in addition to your normal activities?

As the interview progressed, the participants were asked about support or services they had received while providing care. These questions were directed to promote discussion of how caregivers manage the challenges of living with and caring for a spouse with heart failure as well as describing the coping strategies used to manage the daily experience. These experiences were elicited by the following probes:

- Do you receive help from anyone?
- Have there been services that you have needed as a caregiver that you felt you have not received?
- Who do you go to for help and support?

To establish a comparison between present and future, participants were asked a third set of questions and probes:

- What do you expect from present treatment?
- Where do you see yourself and ____ in a year?

Responses to the questions above were expected to reveal the caregivers’ understanding of how this devastating disease and accompanying role changes
transformed interactions and impacted the relationship between the couple. The initial caregiver interview was done in person either in the participant’s home or in a private area in the clinic.

Key to understanding the experience of caregiving across the illness progression of heart failure, the experience must be studied over time. The dynamic nature of caregiving was captured by the follow-up interview questions which include:

- Tell me what has been going on with ____ since our last interview
- Over the last month have you noticed a need for other services?

The caregivers were asked to relate their experiences freely and the context of what they described related to the priority of the caregiving experience during that month. The goal was to capture the dynamic flow of caregiving across the illness progression of heart failure over 12-14 months.

**Interview Sessions**

Interview sessions were scheduled at the convenience of each participant and took place in either their homes or at a mutually agreed upon location where privacy could be maintained. The goal was to schedule an interview approximately each month or after an exacerbation had occurred in the care recipient. Each session began with greetings, explanations, and non-directed questions that helped establish a rapport between the investigator and the participant.

The initial in-depth interview was conducted in person with each participant at a private, mutually convenient location. The initial interview lasted approximately 60-90 minutes in length. The follow-up interviews were conducted either in-person or by telephone with the participant approximately each month or after an exacerbation for at
least one year. The majority of the follow-up interviews were conducted by telephone due to the large geographic area of the sample. The follow-up interviews lasted approximately 30 minutes. The final interview was a summary or exit interview. The approximate length of the final interview was approximately 60 minutes. The final interview either occurred over the phone or in person depending on the geographic location of the participants and the research team. The interviews were digitally recorded and transcribed verbatim. The text of the transcripts was verified against the digital recordings for accuracy. All identifying information was removed from the original transcript by the researcher who conducted the interview.

Field Notes

Field notes were collected and transcribed during the study to describe people, events, situations, and activities that occurred in the course of data collection throughout the study. Field notes provide a record of the researcher’s first hand immersion in the participant’s sphere of life and hold important information about the contexts within which the participants live. Detailed, accurate, and extensive field notes are necessary for a successful qualitative study (Morse & Field, 1995).

The Research Team

The principal investigator and the research assistants were the primary data collectors for the study. All of the research assistants were enrolled in a doctoral program during data collection. The research assistants had all taken at least one course in qualitative methods prior to data collection. The research assistants received additional training on qualitative interviews and data collection prior to start of the study. The research team also had a two-day training session on Atlas.ti.
Bi-monthly research team meetings were held during the study period to ensure consistency in data collection and to update the interview guide based on analysis. A codebook was developed using an iterative process and reviewed by the research team. To ensure consistency among the researchers, the same transcript would be coded by the team prior to the meeting. The codes were compared in the meeting. Differences of opinion were resolved through discussion and consensus. Also during these work sessions the code book was reviewed and updated as needed throughout the simultaneous process of data collection and analysis consistent with the tenets of grounded theory. Team meetings were digitally recorded and transcribed as a part of the dataset in order to preserve analytic insights and to establish an audit trail with significant decisions made during the study. The principal investigator and one research assistant applied the coding scheme to the transcripts using Atlas.ti. At the conclusion of data collection for the original study, each participant consented to additional interviews if necessary for the study.

**Participant Retention**

Based on the longitudinal study design, incentives were instituted to offset participant burden. The first interview took place in person at a place of convenience for the participants such as in the hospital setting, while the participants were in clinic, or at the participants’ home. The follow-up interviews occurred over the phone or during a clinic visit in a private room, whichever was more convenient for the participants. Follow-up interviews were prearranged at a mutually convenient time. The participants each received a $10 gift card to a local convenience store for every interview completed. During the entire data collection period, 20 couples enrolled and were followed between
1 month and 14 months time period. Eighteen couples were followed for 12-14 months (10-12 interviews); one couple was followed for 1 month due to death, and 1 couple for six months as they were unable to complete the study due to illness. During the original study design, participant burden was a concern. However, over the course of data collection it was apparent to all members of the research team that the dyad appreciated and actually enjoyed the monthly follow-ups. In fact, the participants were very vigilant in informing the research team when a hospitalization or complication occurred in the care recipient by notifying the research team by phone.

**Data Management**

The data management process began with the verbatim transcription of the digitally recorded interviews of the original study. Interviews were transcribed verbatim by a trained transcriptionist. In order to reduce threats to validity, once the interviews were transcribed, a member of the research team verified the interviews for accuracy by listening to the digital recording while reviewing the transcript word-by-word. The digital files were sent electronically to the transcriptionist via software with encryption to maintain confidentiality. The interviews were viewed on password protected computers and the original files are stored on an external hard drive in a locked office. The accuracy of the content of the transcribed interviews was verified by the research team. Each original transcript was cleaned of all potentially identifying information such as names of participants, names of health care professionals, and potentially identifying locations. The final result was a cleaned, verified transcript used in data analysis.
Protection of Human Subjects

IRB approval was obtained from The Pennsylvania State University prior to data collection in the original grounded theory work. The following documents were approved by the IRB:

- Recruitment Flyer (Appendix A)
- Participant Consent Form (Appendix B)
- Interview Guide (Appendix C)

Each participant was assigned a code at the beginning of data collection. This code was utilized for all interviews with the participant. The master list linking the codes to the participants is kept in a secure locked location by the principal investigator (Hupcey). All digital files of the interviews contained on the digital recorders were deleted immediately following transcription of the interviews, and the digital files kept on a password protected computer.

Participants in this study were at minimal risk for the loss of confidentiality. Safeguards included the coding of all subject materials to ensure the identity of the participant could not be determined by anyone other than the researcher. All data were kept strictly confidential. This was emphasized at the time of consent as well as in the follow up interviews. All documents pertaining to this research are kept in a secure, locked location by the research team. The transcriptionist completed an IRB training module as well as signed a confidentiality form. All research assistants collecting data completed the IRB training module.

There were no treatments or interventions associated with this study. Participants were informed that they could stop the interview or withdraw from participation at any
time without harm or penalty. Every effort was made to recruit minorities, women, and men for participation in this study. Participants did not report any negative effects from participating in the original study. Participants reported that participation in the study was a positive experience and that verbalizing their feelings and thoughts to someone other than another family member was a therapeutic experience.

**Kitko Study**

For this study, the context was the dynamic course of spousal caregiving of an older patient across the illness progression of heart failure and the types of work experienced by the spousal caregiver over a 12-14 month period. In research circumstances, such as with this study, in which theory does not exist to adequately explain a phenomenon, the grounded theory method is appropriate as it allows for generation of such a theory to describe the basic social psychological process. Therefore, the tenets of grounded theory methodology were utilized for this inquiry. The theory generated by utilizing this method will be embedded or grounded in the empirical data derived from the interviews with the participants who were acting within the specific social context under study (Chenitz & Swanson, 1986). Consistent with the purposes of the study, tenets of grounded theory methods were selected as the method to answer the following research question: What are the types of work experienced in long term spousal caregiving of older patients across the illness progression of heart failure?

**Secondary Analysis of Qualitative Data**

Secondary analysis involves the use of existing data, collected for the purposes of a prior study, to pursue a new research interest from that of the original work (Heaton, 1998; Hinds, Vogel, Clarke-Steffen, 1997). The analysis may involve a new research
question or an alternative perspective on the original question and may be completed by
the original researcher or another researcher (Szabo & Strang, 1997). A secondary
analysis of a quantitative data set is a common approach. In contrast, a secondary
analysis of a qualitative data set has not received the same degree of acceptance. A brief
review of the current literature of the method will be presented as well as adequacy of the
original data set to be utilized in the secondary analysis.

Several methodological issues of conducting a secondary analysis of a qualitative
data set have been identified. Hinds et al. (1997) identify the first issue as the degree to
which the data generated are amenable to a secondary analysis. The “fit” between the
available data and the new research question is clearly the most important issue to resolve
(McArt & McDougal, 1985). Study questions about the same phenomenon or closely
related phenomena are more likely to yield data of appropriate depth and detail (Hinds et
al., 1997).

The second methodological issue related to a secondary analysis relates to the
degree of conceptual specificity needed (Hinds et al., 1997). An original study purpose
that included fixed or predetermined conceptual definitions may limit the exploratory
nature of the secondary analysis. The final methodological issue identified in the
literature is the sensitivity of the researcher to the context of the original study.
According to Hinds et al. (1997) this threat to validity can be minimized if the secondary
researcher was part of the original research team.

Within the context of a rich, large data set it is possible to generate a valid theory
through a secondary analysis of a data set. Empirical support is given to this stance with
the development of the Illness Trajectory (Wiener & Dodd, 1993). This middle range
theory was generated through secondary analysis by a partially adapted grounded theory approach. Consistent with the tenets of grounded theory theoretical sampling should proceed with the simultaneous process of data analysis and collection with the emerging themes guiding the sampling process (Glaser & Strauss, 1967). These requirements cannot be utilized when analyzing secondary data. Although data collection is complete, with a large data set, the iterative cyclical process of analysis and sampling to the point of saturation can still occur within the confines of the existing data set, if the data set is sufficient in terms of size and richness and there is a fit between the original research question and the secondary analysis (Wiener & Dodd, 1993).

Specific to the current research study, several insights may be useful to support the integrity of the research. First, the investigator was part of the original research study and has a dissertation committee with expertise in qualitative methods. The size of the proposed data set is adequate and contains over 200 interviews (digital recordings and transcribed interviews) from a wide range of participants. This is considered a large data set for a qualitative inquiry. According to Oberst (1993), given a large volume of data some semblance of theoretical sampling may occur. Also, in each interview the caregiver had the opportunity to freely dialogue about the previous month which provided very rich data and allowed the participant to introduce almost any topic of concern. Finally, the original research team provided consultation through formal analytic sessions throughout the analysis process of the current study.

**Kitko Sample**

The 20 spousal caregivers of heart failure care recipients ≥ 62 years of age from the Hupcey study were utilized as the sample in the secondary analysis. All interview
transcripts were available for secondary analysis. Data analysis began with the 20 spousal
caregiver interviews in the Hupcey dataset and analysis continued until saturation was
reached with the data set.

Data Analysis

Constant Comparison Method

The constant comparative method as described by Glaser and Strauss (1967; Strauss & Corbin, 1998) was used to generate a middle range grounded theory to discover the types of work experienced in long term spousal caregiving of older adults in the context of heart failure. The purpose of the analysis is to reduce large amounts of data into meaningful categories, then to relate the categories in meaningful ways. The analysis process should convert raw data into concepts or themes. The analysis process is labor intensive and requires much creative thought on the part of the researcher.

The primary goal of this research was to define the types of work experienced in long term spousal caregiving of older patients across the illness progression of heart failure within the context of the Corbin and Strauss (1988) Chronic Illness Management Trajectory Framework. The second goal of this study was to generate a middle range theory of spousal caregiving in heart failure. The analytic procedures that guide constant comparison are performed at every level of analysis as data organize, collapse, and are categorized into higher order abstractions. The discovery of the conceptual themes was accomplished by utilizing the methods of grounded theory. Glaser and Strauss (1967) identified the following four stages in the constant comparative method:
1. Establish categories based on similarity of content in incidents and dissimilarity of content with other categories, with the aim of elucidating the theoretical properties of each category.

2. Compare each incident within each category with the dimensions of the category for integration into a unified whole that reflects the relationship of the dimensions or properties of the category.

3. Examine categories and their properties for underlying uniformities that may reduce the number of categories. Look for theoretical saturation of content.

4. Produce analytic memos to summarize the theoretical explanations.

The multiple levels of coding performed in this analysis began with participants’ empirical descriptions of the phenomena of interest found in the narrative interview data and proceeded inductively towards that identification of emergent theoretical constructs (Glaser, 1978).

Coding techniques.

Each transcript was read word-for-word to enhance the researcher’s familiarity of the interview content. This first read began the open coding process of identifying persistent words, phrases, themes or concepts within the data. The researcher acknowledges that levels of coding often overlap rather than occur in isolation but for clarity of explanation of the development of the codebook, coding techniques are presented as levels.
**Level one: open coding.**

Open coding as defined by Strauss and Corbin (1998) is the analytic process through which concepts are identified and their properties and dimensions discovered. Open coding was performed during a line-by-line read of each interview for key words spoken by the participant. Open coding is an essential step in grounded theory as it facilitates the generation of categories early in the analytic process and allows key words from the participants to organize data that share meaning into categories.

In this study open coding began with a preliminary set of codes that were informed from the analysis of the original Hupcey study as well as informed by the guiding theoretical framework. The transcripts were re-read to validate the first read of the interview transcripts resulting in some revisions that were noted in the margins. During this read of the data set, the set of transcripts were analyzed over the entire data collection period for each participant over the 12-14 month period to capture the dynamic work of caregiving. It was also evident during this first level of coding (based on the transcripts of the 20 spousal caregivers) that saturation had been obtained as no new categories were identified in the data.

**Level two: axial coding**

Whereas open coding is used to break down the data and to identify first level concepts and categories, axial coding is the term used to denote the way in which connections are made in new ways between categories and sub categories according to obvious fit. Strauss and Corbin (1998) use the term “axial” because “coding occurs around the axis of a category, linking categories at the level of properties and dimension”
With each higher level coding operation, it is expected that the categorization of coded data becomes more selective and abstract.

Level two coding proceeded with continued in depth analysis of data utilizing axial coding. This was accomplished by constant comparison within and across categories and subcategories to form more precise and complete explanations about the phenomena. Notations were made in the margins of the transcripts and the codebook was updated and revised during this process to provide an audit trail of decision making.

Ongoing analysis of categorized data led to further condensing of level one codes. The determination of which specific categories that traveled to Codebook 2 was facilitated by constant comparison of emergent meanings and conceptualizations. In this process, some initial categories of coded data were set aside due to lack of significance related to the research questions or redundancy with other sub-categories. Examples of subcategories set aside at this juncture included description of the spouse prior to heart failure diagnosis and reaction to the diagnosis.

The higher level of abstraction in Codebook 2 exhibited the major categories or emerging concepts that represented the basic structural factors of the process under study and were decidedly representative of the meaning captured by the participant’s own words.

**Level three: selective coding**

During level three analysis, the final level of coding, theorizing takes place. Throughout the selective coding process of integrating and refining categories a heightened level of abstraction is performed to delineate thematic conceptualizations (Strauss & Corbin, 1998). In this study, selective coding guided the emergence of the
central thematic concepts represented in Codebook 3 (Appendix D). Selective coding served as the prelude to the emergence of the core variable. The core variable accounts for a large part of the variation in the social processes and represents an important integrative factor (Strauss & Corbin, 1988). Through the interaction between the researcher and the data, the analytic gestalt described by Strauss and Corbin (1998) emerged as a cumulative body of findings. The relationships between the thematic concepts and the core variable emerged from the rich data given by the participants and support the grounded theory that will be reported in Chapter 4 and discussed in Chapter 5.

This level of analysis requires that the researcher have “theoretical sensitivity” (Strauss & Corbin, 1998, p.42). The term refers to the investigator’s ability to use insight to develop conceptual rather that concrete terms. Strauss and Corbin (1998) describe the development of such sensitivity from three sources: the literature, professional experience, and personal experiences. This theoretical sensitivity allows the researcher, from the participants’ frame of reference, to synthesize what has been happening, weave the once fragmented data into a comprehensive pattern that is the theory, and provide a clear interpretation of the theory substantiated by the data and the existing literature (Strauss & Corbin, 1998).

As with original research, secondary analysis must also address the issues of methodological rigor. Therefore, the same criteria must be applied to secondary analysis as in the original analysis (Szabo & Strang, 1997).
Maintaining Scientific Rigor

Traditional approaches to validity and reliability are most useful for studies based on a quantitative design (Lincoln & Guba, 1985). In qualitative studies, such as this grounded theory study, other means of assuring quality include demonstration of rigor and trustworthiness.

The methodology described utilizes the researcher as the instrument. The flexibility of the design, complexity of the analysis, and conceptualization of the phenomenon require a significant investment on behalf of the researcher. This form of inquiry of the lived experience cannot avoid observer bias; rather conceptualization and assumptions are an inherent part of the inquiry (Morse & Field, 1995). The goal of rigor in qualitative research is to accurately represent study participants’ experiences and is demonstrated through attention to and confirmation of information discovery. Lincoln and Guba (1985) utilized the terms credibility, confirmability, dependability, and transferability to ensure the reliability and validity of a qualitative study.

Credibility

Lincoln and Guba (1985) suggest that credibility be the criterion against which the truth value of qualitative research be evaluated. A qualitative study is credible when other readers are able to recognize the experience when confronted with it after having only read about in the study. This study established credibility following the guidelines set forth by Lincoln and Guba (1985). This researcher has considerable credibility working with older chronically ill adults and their families. The researcher also demonstrate credibility in qualitative methodology by serving as a research assistant on multiple qualitative studies with some of the leaders in the field of nursing research.
utilizing qualitative methodology. The researcher was also part of the research team in the original study. Another way that credibility was enhanced is through the process of peer debriefing with the dissertation chairperson. The process of debriefing is when a trusted mentor or colleague presents opposing viewpoints for the researcher to consider in the analysis by facilitating confirmation or rejection of evolving ideas and decisions made by the researcher.

**Transferability**

Transferability refers to the probability that the study findings have meaning to others in similar settings (Lincoln & Guba, 1985). As Lincoln and Guba (1985) described, the researcher’s responsibility is to provide adequate information to make a judgment of transferability possible. When the interview data contains a thick and rich description of the phenomenon of interest, the findings are more likely to be transferable to a similar population. To enhance the process of obtaining this thick and rich description, the interview guide for the Hupcey study was designed with broad, open-ended questions and multiple probes to elicit a very rich description of the phenomenon. During the bi-monthly team meetings in the Hupcey study, the interview guide was changed and adapted based on the data that had been collected.

**Dependability**

An audit trail enhances both the dependability of the research process and the confirmability of the research product (Lincoln & Guba, 1985). An audit trail provides a means to track the entire qualitative research project from start to finish. A study and its findings are auditable when another researcher can clearly follow the decision trail utilized by the investigator in the study. In addition, another researcher could arrive at
the same or comparable but not contradictory conclusions given the researcher data. In consultation with the dissertation chair, group analysis meetings were scheduled to achieve dependability in this study. The group consisted of the dissertation chair as well as the other two research assistants from the Hupcey study. The group analysis meeting was scheduled after the first ten interviews were coded. Each of the group members were provided the complete, unmarked set of interviews as well as the initial coding scheme developed. The goal of the meeting was to ensure consistency of the coding scheme and categories, as all of the group members were familiar with the data. Based on the consensus of the group, the coding scheme and categories was revised. Field notes were transcribed from the analysis session.

**Confirmability**

Lincoln and Guba (1985) suggest that confirmability be the criterion of neutrality in qualitative research. Confirmability is concerned with assuring that the data are not based on research bias. The integrity of the findings is rooted in the data, the interpretations, and the outcomes of the study. The inquiry trail includes all raw data gathered, produced, and utilized to interpret and assemble findings, culminating in the final presentation of the research. Codebooks were developed for each level of coding operations.

**Protection of Human Subjects**

As this investigator was part of the original Hupcey study as listed on the consent form, the Institutional Review Board of The Pennsylvania State University was contacted to determine if additional IRB clearance was necessary. It was determined by the IRB and the dissertation committee that the original consent was sufficient for the secondary
analysis. The cleaned transcripts with no identifying information were utilized for the secondary analysis in order to maintain the levels of confidentiality in the Hupcey study.

Chapter Summary

The rationale for the use of qualitative secondary analysis and the relevant elements of the data collection and analysis have been presented. The chapters that follow will present the findings of this research. Chapter Four will describe the results of the data analysis as it pertains to the emerging theory. Chapter Five will present an overview of the significant findings, findings in relations to the model, implications of the findings, study strengths and limitations, recommendations for future research, research based on the emergent theory, and conclusions.
Chapter 4

Results

Analysis and interpretation of the results of this study utilizing the tenets of grounded theory methods are presented in this chapter. The conceptual framework that guided this investigation continued to make important contributions throughout the analysis and interpretation of findings. The Corbin and Strauss chronic illness management theory (1988) informed the core variable of committed obligation and illuminated the perspectives of the spousal caregivers as they explained the types of work experienced across the illness progression of heart failure. The core variable, committed obligation emerged from the analysis and interpretation of spousal caregivers’ descriptions of the experience of caring for a heart failure care recipient over time.

Within the natural setting of the marriage where the work of caregiving occurred, the Corbin and Strauss chronic illness management theory (1988) allowed for the full understanding of what daily life was like for the spousal caregivers as they lived it, experienced it, and gave it new meaning. The perspective provided by the Corbin and Strauss theory guided the interpretation of the work the caregivers experienced while caring for a spouse with heart failure. The key themes that emerged from the data will be presented in this chapter as well as a discussion of the core variable and the resulting middle range theory based on the data. Following is a description of the study participants which provides a demographic profile of the caregiving spouses.
Participant Demographics

According to Lincoln and Guba (1985) the demographic data assist researchers with determining the meaning and applicability of a study’s results to other similar situations. In grounded theory studies, the demographic data are important for comparing cases and verifying a theoretical sample. While it is expected that the findings of the study may only be applicable only to the study group, the description of the sample provides the research community guidelines for replication or continued work in this context (Table 4.1).

Table 4-1: Participant Demographics

<table>
<thead>
<tr>
<th>ID #</th>
<th>Spousal Caregiver Gender</th>
<th>Caregiver Age in Years</th>
<th>Care Recipient’s Age</th>
<th>Years Married</th>
<th>Years in CG Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>AHA 1</td>
<td>Female</td>
<td>69</td>
<td>74</td>
<td>40 years</td>
<td>4 years</td>
</tr>
<tr>
<td>AHA 2</td>
<td>Male</td>
<td>68</td>
<td>65</td>
<td>46 years</td>
<td>2 years</td>
</tr>
<tr>
<td>AHA 3</td>
<td>Female</td>
<td>69</td>
<td>71</td>
<td>51 years</td>
<td>1 year</td>
</tr>
<tr>
<td>AHA 4</td>
<td>Male</td>
<td>73</td>
<td>74</td>
<td>52 years</td>
<td>4 years</td>
</tr>
<tr>
<td>AHA 5</td>
<td>Female</td>
<td>63</td>
<td>65</td>
<td>44 years</td>
<td>9 years</td>
</tr>
<tr>
<td>AHA 6</td>
<td>Female</td>
<td>71</td>
<td>71</td>
<td>51 years</td>
<td>9 years</td>
</tr>
<tr>
<td>AHA 7</td>
<td>Female</td>
<td>68</td>
<td>79</td>
<td>45 years</td>
<td>2 years</td>
</tr>
<tr>
<td>AHA 8</td>
<td>Female</td>
<td>69</td>
<td>75</td>
<td>50 years</td>
<td>2 years</td>
</tr>
<tr>
<td>AHA 9</td>
<td>Female</td>
<td>46</td>
<td>75</td>
<td>14 years</td>
<td>2 years</td>
</tr>
<tr>
<td>AHA 10</td>
<td>Female</td>
<td>71</td>
<td>72</td>
<td>49 years</td>
<td>8 years</td>
</tr>
<tr>
<td>AHA 11</td>
<td>Female</td>
<td>68</td>
<td>68</td>
<td>46 years</td>
<td>6 years</td>
</tr>
<tr>
<td>AHA</td>
<td>Gender</td>
<td>Age</td>
<td>Length of Marriage</td>
<td>Time in Caregiving Role</td>
<td></td>
</tr>
<tr>
<td>-------</td>
<td>--------</td>
<td>-----</td>
<td>--------------------</td>
<td>-------------------------</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Male</td>
<td>67</td>
<td>62</td>
<td>45 years</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Female</td>
<td>68</td>
<td>70</td>
<td>22 years</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Female</td>
<td>62</td>
<td>64</td>
<td>43 years</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Male</td>
<td>73</td>
<td>71</td>
<td>53 years</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Female</td>
<td>53</td>
<td>65</td>
<td>6 years</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Male</td>
<td>75</td>
<td>73</td>
<td>55 years</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Female</td>
<td>64</td>
<td>65</td>
<td>45 years</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Male</td>
<td>65</td>
<td>65</td>
<td>45 years</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Female</td>
<td>78</td>
<td>77</td>
<td>54 years</td>
<td></td>
</tr>
</tbody>
</table>

The sample for this secondary analysis was comprised of 20 spousal caregivers of partners with heart failure. At the time the study was conducted, all of the caregiving spouses were actively in the caregiving role. Participants at the beginning of this study ranged in age from 46-78 years, with a mean age of 67. Fourteen of the caregivers were female and 6 were male. Years of marriage ranged from 6-55 years, with a mean of 43 years of marriage. The self reported length of time in the caregiving role at the beginning of the study ranged from 2 months to 9 years with a mean of 4 years in the caregiving role. In response to the interview questions and probes that elicited information about the marital state, every one of the participants described themselves in a committed relationship with their spouse.

All of the participants gave extensive accounts of the various types of work experienced while providing care to a spouse with heart failure. The types of work
experienced varied dynamically each month over the 12-14 month period. The open
ended follow-up interviews allowed the caregiver to freely discuss the type of work at the
fore of their consciousness for that month. Constant comparison and abstraction of the
categories led to the emergence of the seven central thematic concepts that provide
answers to the research question of: What are the types of work experienced in long term
spousal caregiving in older adults across the illness progression of heart failure?

The key themes of the caregiving role were: the work of living with the illness,
the work of providing care, the work of navigating the system, the work of normalcy, the
work of vigilance, the work of managing the household, and the work of maintaining self.
The key themes will be discussed in detail in this section.

Themes

The Work of Providing Care

The work of providing care encompassed both the physical and psychological
provisions of care to the spouse. The physical work of providing care included providing
assistance with activities of daily living, medication management, daily weights,
assessment of incisions, as well as assessing for edema, and travel to and from doctors
appointments and hospitalizations. The psychological aspects of providing care
encompassed everything the caregiver did to maintain the psychological well being of the
care recipient such as counseling, encouraging, and developing strategies to combat
depression in the spouse with heart failure.

The participants spoke of the variety of work involved in providing care to a
spouse with heart failure and the impact this work had on the role of caregiving. The rich
narratives illuminate both the physical and psychological work of providing care. A
recurrent statement expressed by many of the spousal caregivers to describe their role was of a “learning process.” Many of the spousal participants spoke of bringing home an ill spouse after a hospitalization for heart failure. The feelings assuming this role were aptly summarized by a male caregiver when he first brought home his wife who had just spent a week in a major medical center after the exacerbation of her heart failure:

“But no, I really did not have anyone sit down with me and say these are the things you need to do-in fact I told the cardiologist I did not think she was ready to go home because she had only been off the IVs and on her oral medications for 2 days. I was sort of you know thrown to the wolves really.”

The work of providing care was expressed throughout the interviews. It was threaded throughout the interviews regardless of the spouse’s medical condition; during times of exacerbations, after times of hospitalizations, as well as at times of relative medical stability. This was expressed by the spousal caregivers with terms such as “planning”, “patience” and “organized”. The wife of a couple who still frequently travels stated:

“You have to be organized to do this work. I have a diary with his daily weights and a current list of his meds, I also write down every appointment with every doctor. I have to, he sees so many. When he received his pacer he was part of an experimental group. Some got pacers with defibrillators and some did not. He did not so we bought our own AED. At home I keep it in the bedroom because most heart attacks occur in the morning, I read that. When we travel, I take it with me, I have a note from the doctor, I also carry my own scale and his most current EKG just to be sure.”
One of the most prevalent issues within the theme of the work of providing care was the management of medications. Although few of the participants reported physically administering the medications to their spouse, there was a considerable amount of work in managing the medications including filling pill boxes, maintaining the supply of medications through mail order or pharmacy, and maintaining correct dosages especially for drugs which required altering drug dosages such as: diuretics, anticoagulants, or steroids. This issue was best summarized in the following statements from various spousal caregivers:

“After a hospitalization, that is the hardest, it is tough keeping up with the changes.”

“When I am not with him and its med time, I always call on my cell phone as a reminder.”

“My job as a caregiver is mostly nagging him to take his meds.”

“It is our Sunday ritual to fill the med box for the week—he is up to 23 per day.”

“The Coumadin is the hardest, I make a mistake with that and it could kill him.”

“I always have my diary with his daily weight and current med list.”

“Even though he takes his meds, I double check to make sure he is correct.”

“All of these meds, all of these changes, we have a pharmaceutical warehouse of meds that she could not tolerate.”
The physical aspect of providing care was just a subset of this theme. Also within the theme of providing care was the psychological work of providing care. The spousal participants detailed the psychological work that was an integral part of their caregiving role. Many of the caregivers gave very detailed accounts of how they combat frequent bouts of depression in their spouse. Listed below is a summary of statements by the caregivers that aptly capture this phenomenon:

“I am always trying to talk her into the positive.”
“Keeping his spirits up—that is the most difficult part of my job.”
“Build up her spirits that is what I do when she is down.”
“I always tell him, honey the cup is half full not half empty.”
“I can sum my role up in three words, I am a cheerleader, drill sergeant, and negotiator.”

Evident throughout the detailed spousal accounts, was that the work of providing care was not always easy and at times very overwhelming for the caregivers. A 68-year-old female summarized this by her statement:

“I always had felt you know that the doctors could fix everything. You know they gave him pills and fixed it or did something to fix him. Well this is the first time I realized that if anything happened to him on the way home and I was driving and something I was just not sure what I would do. And all of a sudden I just thought I can’t do this. I cannot do this anymore; over and over again I can’t do it anymore and I just turned the car right around and my heart was pounding and I went to the emergency room and I said I don’t know what’s wrong but I have to come in here.”
The work of providing care varied throughout the course of heart failure. At times the prominent type of care manifested by the caregivers was in the physical realm and at times, the psychological realm was at the fore of the discussions. There were also instances in which a mix of physical and psychological care were evident on the part of the caregivers.

**The Work of Living with the Illness**

The work of living with the illness was the second theme to emerge from the data. This theme was very aptly captured by the longitudinal interviews. At times of medical stability in the care recipient, the spouses used terms such as acceptance or hope, and some actually offered positive glimpses of what the future held for the couple. In times of illness exacerbations in the care recipient, the spouses maintained a guarded day-to-day outlook.

During the times when the care recipients were medically stable, the caregivers talked of how they were keenly aware that their spouses’ conditions would not improve and expressed how they had accepted the illness. They also talked about their future with heart failure and many of the participants used the same term of “hope” when discussing their spouse.

“We just hang in there and hope for the best.”

“I hope this new device will help her.”

“I hope he is like this next month, it could be so much worse.”

When the spouse was having medical issues related to their heart failure, the terminology utilized by the spouse was very different to describe living with the illness as opposed to when the spouse was in a more stable period. When the spouse was not stable
the caregivers became very temporally based in the terms they used to describe living with the illness. The most common phrases used by the participants included:

“Living day to day.”

“One day at a time, that is all we can do.”

“Day to day, we don’t look any further.”

“If he does not get a heart soon, he may not be here when I talk to you again.”

“You never know day to day what will happen.”

“Maybe there will be a better day tomorrow.”

The uncertainty related to the illness progression of heart failure experienced by the care recipient also had an impact on the concerns expressed by the caregivers. The responses expressed by the spouses moved in tandem with the illness progression of the heart failure care recipient. When the care recipient was in a stable portion of the heart failure trajectory the caregivers expressed concerns such as “lots of prayers with constant worry and concern”, “patience” and summarized by a 68-year-old-female as “constantly there even when he is having good days.”

The emotions expressed by the caregivers also ebbed and flowed with the heart failure progression of the spouse. When the spouse was not medically stable the caregivers used terms such as: “scared” to describe experiences such as a cardiac arrest in the hospital, the firing of an internal cardiac defibrillator, the new onset of a cough, or waiting for a heart transplant. A 68 year-old-male caring for his wife after a hospital admission when she required assistance with many of her activities of daily living described his emotions as “overwhelmed and afraid to look in the room to see if she is still breathing.” The emotions at times reached critical levels for these caregivers as
they worked to live with the illness. A 53-year-old teacher describes her emotions as she was caring for her husband who suffered from depression after his heart transplant.

“I mean I am thinking here you have a new quality of life and you’re so depressed. He was miserable. Yeah that was tough for me to watch. I couldn’t stand it. I started screaming one day, and I didn’t mean to but I couldn’t stand it already.”

Within the theme of the work of living with the illness, a 69-year-old female very succinctly captured the dynamic emotions experienced while providing care to her 71-year-old husband when she stated, “Not that I am suffering with heart failure but I am suffering along with him just the same” during an interview in which her husband was having angina with the slightest activity and was dealing with depression. When the husband’s medication regimen had been adjusted in during a subsequent hospitalization and an antidepressant added to his regimen, the caregiver discussed how they had “hope back in their lives again” and added, “when he is doing good, I’m much better.”

As the spouses reflected back over the 12-14 months of interviews, many had various terms to describe the experience of living with a chronic illness such as heart failure. Consistent with the multiple heart failure trajectories described by Hupcey et al. (2008), the terms used to describe living with the illness varied dependent on how heart failure was progressing in the care recipient. A 71-year-old female caregiver who has been caring for her husband over the past 9 years describes the experience as “it has been a long haul, a roller coaster ride if you will, but I want more.” A 68-old-male who has been caring for his spouse with advanced cardiomyopathy over the past seven years
described the experience as a “slow slippery slide.” A 68-year-old female who has been providing care to her relatively stable husband over the past 2 year states:

“Concerned-I mean we were riding along a pretty smooth road for quite a while. So I think anytime you have a bump in the road you are concerned. It seems like I am always waiting for the next event.”

A 73-year-old male has been providing care for his wife over the past five years in which she has had multiple hospitalizations due to her heart failure. Most recently she received an internal cardiac defibrillator and a new valve. He describes living with heart failure as:

“We are living on the edge you never know what will happen next, it has been quite an adventure. Some days it is smooth sailing and the next you are flying by the seat of your pants. It is a pendulum back and forth.”

A 46-year-old female has been caring for her 75-year-old husband for approximately 2 years describes living with heart failure in these terms:

“This whole experience is like being in an ocean. Sometimes it’s calm and other times it’s quite choppy. The problem is you don’t have a radar screen where you can, you know Doppler radar that you can predict the storm coming in. It has been a long haul for quite some time I would say close to a year I didn’t know what normal felt like any longer. My life had lost its sense of normalcy. It was so unpredictable from day to day.”

These quotes exemplify the dynamic and unpredictable trajectory of living with a spouse with heart failure. The serial interviews provided rich data which aptly
illuminated the experience of living with heart failure from the spousal caregiver perspective as well as the changes experienced over time.

The Work of Navigating “The System”

The work of navigating the system was another thematic concept in the role of caregiving. This theme emerged from the collapsing of several categories of clustered instances (i.e. healthcare providers, insurance issues, and local versus specialty care) of raw data revealing participants’ descriptions of the work involved navigating complex systems as they cared for their spouse. “The system” encompassed any large entity which involved time and work on the part of the spousal caregiver. Systems included complex healthcare systems, insurance companies, and government institutions as would be necessary for medical disability.

Spousal caregivers spoke of the planning and coordination needed to navigate several healthcare systems. For those that lived a distance from a tertiary referral center, many care recipients had their heart failure managed by a local family physician as well. These various levels of care required coordinated work on the part of the caregiver as evidenced by the following excerpt of the female spouse whose husband is on the transplant list at a large tertiary medical center but is also followed by a local physician which is much closer to home:

“I am not sure which hospital to go to. I guess if he has an episode or whatever we take him to the local hospital, I guess unless it’s his, oh what do you call it, the defibrillator, then I guess he would go to (local) hospital for that but then they would transfer him to (large medical center) if it was more than that or if there was a heart.”
At times navigating the complex systems became a source of angst for the spousal caregivers. This was especially evident in the following quote from this 68–year-old caregiver who resides in a rural community and whose husband is treated at a tertiary medical center about 2 hours away:

“It’s hard because you do not know who to turn to when something is wrong. Like the one local heart doctor we’re going to locally made a comment that “how am I going to work with him when I only see him once a year?” The doctor in [major medical center] said it was perfectly fine to visit once a year and have his defibrillator checked and see the heart failure specialist. They think it is ok so he does not have to travel out there in the winter you know. But the local doctor said “I don’t know how I can only see you once a year.” Then the family doctor will say sometimes to him “well what are we seeing you now for? Don’t you go to the doctor from [major medical center]?” Like he does not own him as a patient anymore. So we feel lost between the two systems and are never sure who to call when we have questions or issues.”

For the advanced heart failure care recipients on the transplant list, navigating the health care system posed special challenges. This is illustrated by a couple who lived 2.5 hours from the major tertiary medical center. The wife was being interviewed with the husband in the ICU of the major referral hospital. Due to her husband’s failing heart, the physician’s had just made the decision to keep her husband in the hospital until a heart became available:

“That takes the pressure off of me as far as if something should happen we’re 2 ½ hours away and we would have to stop at a band-aid hospital and they would not
be able to do anything for him then I’ll have to live with that the rest of my life
that I could not help him. Here if something should happen I mean it’s just God’s
will and that is it, but at least I had him in the safest place I could have put him.”

“The system” was not limited to navigating complex levels of healthcare but also
encompassed dealing with complex systems such as medical insurance. The complex
health insurance system and the work required to navigate the system was very aptly
described by a 62-year-old caregiver who was caring for her husband age 64 over the past
8 years. His condition had deteriorated to the point that he was on the heart transplant
list. This couple struggled that within the year, when he turned 65 years of age, he would
be dropped from disability and his medical insurance through his previous workplace in
which they paid the premium and switched over to Medicare. This switch would then
dramatically increase the out-of-pocket expenses for his heart transplant. The couple in
addition to dealing with the stresses of needing a heart transplant was also struggling to
find a medical supplement that would accept him due to his preexisting condition:

“This insurance issue is weighing on him considerably since he turns 65 in
February. That is why we’re gonna stay with the COBRA, it’s gonna be very
expensive for us to keep the COBRA but if we were-cuse he had checked in to
possibly changing to another insurance there is a 6 month waiting period for a
condition and if by some wild chance a heart transplant would come up in that
period of time we wouldn’t have any insurance for him. But, that is why we were
kind of hoping that you know certain things would happen sooner than later. See
90% of the problem isn’t with the heart transplant it’s the financial problems that
go along with it.”
Choosing a prescription drug plan was unique to this cohort during this period of time as they were involved with the government passing of the Medicare Prescription Drug, Improvement, and Modernization Act (MMA). The spouses were very much involved in the implementation of the plan which for some required changing or adopting new prescription plans as a part of the new law. The MMA posed as yet another complex system that required navigating on the part of the caregivers. Many of the heart failure care recipients were on multiple medications and choosing a drug plan became a very complex decision for some of the participants as evidenced by this female caregiver who attended several meetings regarding the implementation of the MMA law prior to making a decision:

“There were 2 meetings for them to impart information on the new plans and you to receive information...well you know people’s heads were just spinning. I came home and I did a spreadsheet and put down what each one offered and then I actually called down to (major medical center) the financial office and I made an appointment to go in because we don’t want to choose the wrong thing. We did not pick the cheapest plan because the drugs are mail order and I think there are advantages to a pharmacy as quickly as his drugs change. I also like the benefit of being able to talk to the pharmacist or to someone who knows everything he is taking.”

The above excerpts that exemplify navigating the system, speak volumes regarding the amount of work required on the part of the spousal caregivers as only one of the thematic concepts in the role of the caregiver.
Work of Maintaining Self

The thematic concept of maintaining self encompassed the physical and psychological status of the caregiver and what tactics they used to maintain their health in the midst of providing care to their spouse. Many of the spousal caregivers had health issues of their own to deal with but discussing how they maintained self was usually not a topic of the interviews. Usually the discussion of the issues of maintaining self did not occur without a direct prompt. The caregivers discussed strategies they used to deal with the stresses of providing care including, praying, studying the bible, meeting a friend for coffee, exercising, working on crafts, and even babysitting grandchildren.

Several of the caregivers required medical interventions for their own health problems but did not even discuss having them taken care of until their spouse was medically stable. A 71-year-old female caregiver summarized her own health issues:

“In fact today, I will call the doctor. I have a prolapsed bladder and it’s really bothering me lately and now that he is feeling better and about I want to look into having it surgically corrected.”

Several of the caregivers also discussed a lack of support and how that impacted the work involved with being a caregiver. This issue was especially salient when there was a crisis or exacerbation in the care recipient. A female caregiver describes the lack of family in the area as “difficult for me as a caregiver.” She continues by describing periods of providing care that this lack of support for her was especially difficult:

“I mean one time when he was in afib and they wanted to convert him that night. I mean I couldn’t have any one of my siblings fly in and I don’t like imposing on my
friends or colleagues that way and so there I am alone thinking I wish there was someone, anyone that I could just call and tell what was going on.”

This sentiment was expressed by another female caregiver who does have family in the area but her husband is treated at a tertiary medical center 3 hours away:

“I stay with him in fact in a bed right beside him when he is there. It is too much to ask the kids to come, they would, but they all have lives of their own. The second time he had his defibrillator replaced they had him there in the bed and he started talking real funny and all of the nurses were around him asking him questions like something was really wrong. They immediately thought he was having a stroke. I just started to shake. The nurse was real nice and she put her arm around me and I calmed down. But you know nobody is ever with me.”

The work of maintaining self, although an integral part of the caregiving role, very rarely seemed to be the main topic of discussion during the interviews for the participants in this study. If there was time available or if the spouse was medically stable, the caregivers took time for themselves but if the spouse was not stable, the work of maintaining self was rarely discussed.

**The Work of Managing the Household**

The work of managing the household went on in spite of the spouse’s illness. This thematic concept emerged from the data and included all of the work required to maintain the household. This theme encompassed the work required to maintain finances, the impact the spousal illness had on the employment of the caregiver, the changing roles of the household necessitated by the spouse’s inability to maintain previous roles secondary to heart failure, the discussions of not being able to maintain
their current residence, and how the caregivers mobilized help to keep the household going throughout the course of their spouse’s heart failure.

Many of the spousal caregivers spoke of the financial impact of heart failure and how this was one more area of “work” in which they had to address in order to maintain their marriage and lives together. A couple married for 54 years spoke of the enormous impact the cost of medications had on their finances:

“Well we are now in the doughnut hole which means $400.00 per month for medicine. We will be in the hole for August-December. Our sons are –I don’t know we must have been talking to them and they want to bail us out some on the doughnut hole. They think we are destitute. I said oh my word no we are not destitute yet boys. But we are considering a reverse mortgage on our house to cover our med expenses. And I am considering getting a job and I have always been a housewife but $400 a month is a lot of extra money on a fixed income.”

This theme of financial concerns was threaded throughout the interviews of the spousal caregivers and added an additional dimension of work to their role as evidenced by the following interview excerpt from a 73-year-old male caregiver:

“Every time you turn around there is a new pill being put on and thank goodness for drug some copay you know prescription coverage. So that helps. And of course I’m trying to set up monthly payments on our hospital costs. We have about 8 or 10 different bills each month you know from doctors and hospitals. So her meds—that is why I am working. I do not like to leave her alone but those copays add up.”
The work of managing the household also required at times what appeared as complex coordination on the part of the caregiver as they attempted to balance the multiple facets of caregiving. This coordination is illustrated as many of the caregivers made work decision not solely on financial reasons but also attempted to balance work with their caregiving role as much as possible. Several key instances are highlight by the following quotes from several different caregivers:

“You know I probably do 99% of the driving, although he knows when he goes up to (Large Medical Center) this next time, he’ll be going up alone because I have to work.”

“Like I said my plan was to drive bus until my kids graduated and then get another job. But because of what was going on with (husband), I just thought driving the school bus was much more convenient, I don’t have to worry. I can come home and check on him between runs or I can call my boss in the middle of the night and tell him my husband is in the hospital.”

“I work evenings so that I can get her to her doctor’s appointments and be with her most of the day. I am here to keep track of things.”

“I work a few hours in the morning. It keeps me sane. I work from 6 a.m. until 11 a.m. each day. She is so tired she usually does not get up until I come home and I get her pills and we have lunch together. That is what works for us.”
“Thank goodness I have a kind of job where it’s autonomous and I take care of my classes, I can manage and rearrange everything in my world in a moment’s notice. I meant there are certain times where I just need to be where I need to be but frankly my philosophy is that my husband comes first. I can always find another job. I can’t find another husband. You just do the best that you can.”

“Well I completely retired after he went into failure you know kind of cause I realized we had to spend more time on taking care of diet and those kinds of things.”

The theme of managing the household also encompassed the changing roles of the caregiver due to their spouse’s inability to carry out previous roles secondary to their heart failure. For some of the caregivers in the sample this required assuming new household tasks that were previously done by the spouse. A 46-year-old female caregiver described the changing roles of the household:

“It’s just something that you do almost unconsciously but things that require heavy exertion are usually the sticking points in the household because especially with the man it’s been his domain, you know that’s his role to take care of those things around the house and he does not deal well with seeing me doing the heavy work like shoveling, that has always been an issue, but he knows he cannot get out to do it. And my neck hurt so badly, I have a herniated disc in my neck and I was not going to say anything to him about it cause I knew it was a sticky issue to begin with I was just gonna grin and bear it.”
The work of managing the household also prompted several caregivers to talk about changing their place of residence. For some the talk of moving was related to the desire to downsize in order to better manage the household. A 75-year-old male with health issues of his own describes his situation:

“My wife’s health was so bad this year that we just couldn’t think of moving with the shape she was in. Now she’s some better. Next spring it will have to happen. We have to scale down; I can’t take care of this anymore.

For others the talk of the residence change was prompted by the poor health status of the spouse:

“We always figured we’re gonna stay here, but we did not figure on her health getting so bad. So we are probably going to move because it will work out better for her in the long run. Because if everything is on one floor. I hate to buy another house but, uh, yeah, I can’t- I can’t care of her here, not the way I want to.”

As the participants discussed how they managed the various types of work associated with caregiving it was evident from the data, that for some, the priority given to managing the household was easily superceded by other types of work that from the caregiver’s perspective was more important:

“The floors don’t get dusted as quickly as they should, the furniture doesn’t get dusted, we’re not able to cook like we used to. Like I told you before you’re the caregiver and you have to forget about your priorities and make the patient’s priorities your priorities.”
“You walk out the front door and you see nothing but weeds in your flower garden and it’s irritating to me because I knew what it used to look like all the time and I do not have the time to do it.”

“I don’t care what has to be done. Clean when I have the time to clean and so on and so forth. Little things like that that I feel should be done but can be left till the next day.”

For some of the participants, managing the household also included mobilizing resources such as family to assist in times of need. A female caregiver describes her ordeal when after her bus route was completed she needed to take her husband to a doctor’s appointment. Unfortunately, she was delayed due to an accident and describes how she mobilized the resources of her family:

“It just took so much time for them to clear the road. With my cell phone I was able to call my daughter-in-law and she was gonna come down and get (husband) and take him to his appointment.”

Examples of the mobilization of resources to manage the household were evident throughout the interviews. At times the help was mobilized to assist with care of the spouse. It was also utilized to help care for the home such as help with shoveling the snow and mowing the grass.

The work of managing the household was just another piece of the pie in the role of the caregiver and was managed simultaneously with the other types of work. Managing the household as with the other types of work varied in intensity based upon the medical status of the spouse.
Work of Vigilance

The work of vigilance was the sixth theme to emerge from the data. The work of vigilance encompassed the ongoing work of caring for someone with heart failure. Vigilance was the constant awareness that traversed across the illness progression of heart failure despite the care recipient’s medical condition. The work of vigilance was the constant monitoring and watchfulness on the part of the caregiver that occurred to some degree even in the most stable of times in regards to the spouse’s heart failure.

For the participants in the sample who still maintained employment the work of vigilance took on a heightened awareness as they had to leave their spouse alone for periods of time. A 46-year-old professor who cared for her 75-year-old husband detailed the work of vigilance while she still maintained a demanding work schedule.

“Every morning I put my ear to his chest and listen to his heart, that is how we first discovered he was in atrial fibrillation so now I do it every morning before I leave. I monitor him very closely and there are days in which I do not feel comfortable leaving for work so those days I work at home. I call everyday from work and we have our routine, if I am not aware of anything he had planned for the day, I then immediately call my neighbor to check on him.”

A 62-year-old female discusses why she continues to drive bus as her employment. Here employee is very flexible with scheduling which permits her to adjust her schedule as needed due to her husband’s illness.

“After my morning run I am able to come home and check on him. He has the Lifeline button for when I am gone so I do not worry as much. When I have a
break I always call from my cell phone. He is a man of few words but I know that he is ok.”

The work of vigilance continued even for this 53-year-old female who was caring for her 65-year-old husband who had just received a heart transplant. She had just returned to work as a school teacher and her husband was home alone. He was suffering from depression after the transplant and he was also a Type II diabetic. He was having glucose control issues as he was tapering down one of his steroids as part of his anti-rejection regimen.

“We just traded in on a new set of issues after the transplant. I still worry and I hate to leave him to go to work. I have special permission from the superintendent to have my phone on in class. I call everyday to check on him. I was at a conference when he would not answer the phone. I called my niece who lives nearby to check on him. I was an absolute mess until she called me back that he was ok. His sugars have been so out of whack due to his medication adjustments. They have been going down into the 40s, I just hate to leave him alone.”

The work of vigilance was evident even in those caregivers who did not leave the home for employment. A 62-year-old female described her watchfulness as she monitors her husband who is awaiting a heart transplant. He was not moving up on the list in priority for a heart transplant due to his stable hemodynamic numbers from the heart catheterization but she could see him getting worse each day.

“I see him every day, they are just little subtle changes, they are not showing up in the numbers the doctors are concerned with but I see it.”
A 69-year-old female who has been caring for her husband over the past two years discusses how she manages the work of vigilance in conjunction with the other types of work of caregiving.

“I plan my day by the color of his face, that tells it all. If his color is not right, I will not leave him alone, everything can wait. Even on his good days when I do leave the house I have my phone and I call and check on him.”

A 71-year-old female who has been caring for her husband for the past nine years illustrates how her watchfulness of her husband’s condition has also been dynamic over the years and how she has adapted to these changes.

“I used to be able to tell when he was filling up with fluid, he would wheeze. I would hear the wheezing, but now there’s nothing you know. I do not detect anything. So I am much more watchful, I do not let him go anywhere alone. I even sit on the chair by the window and watch him mow the grass.”

Consistent with the other themes of the work of caregiving, the work of vigilance occurred throughout the experience of providing care to a spouse with heart failure and occurred in conjunction with all of the other types of work described by the caregivers.

**The Work of Normalcy**

The final theme identified from the data was the work of normalcy. The theme of normalcy was defined by several key concepts that emerged from the data. The work of normalcy included all of the work by the caregiver to establish some type of routine or normal in everyday life in light of the spouse’s heart failure. It encompassed activities such as flexible planning, anticipating the needs of the spouse, planning for the future, and negotiating.
The work of normalcy as with all of the other themes changed in tandem with the care recipient as they experienced illness exacerbations as well as medical stability in the course of their heart failure. As summarized by a male caregiver who has been providing care to his wife for seven years, “I would like us to be-to have some kind of normal life.” For the caregivers normal was reframed in the context of accepting the chronic nature of heart failure as evidenced by, “I know he will never get better but we have to figure out how to live our lives with this.”

Flexibility on the part of the caregiver was integral to the work of normalcy. In order to maintain normalcy much of the flexibility on the part of the caregiver occurred behind the scenes and away from the spouse. As one caregiver put it, “planned to be unplanned.”

In order to maintain some sense of normalcy, the caregivers worked to anticipate the needs of the spouse in the routine of caregiving. A 68-year-old male caregiver who was caring for his wife stated:

“I try to anticipate her needs and I adjust my routine around hers, I have a chair midway down the hallway in case she needs to take a break, I have water bottles placed in the areas in which she routinely needs them.”

If the spouse was in a stable phase of the heart failure trajectory the caregivers worked to re-establish normal routines that existed prior to the illness or occurred during more medically stable times. For many of the caregivers this entailed planning vacations. But even vacation planning in light of the heart failure was work. A 71-year-old female caregiver describes:
“We used to love to go to Bar Harbor, it is so peaceful and beautiful. (Husband) is well enough for me to plan a trip but I am concerned, there is not a major medical center near there and I am fearful to be away from his doctors. I will still plan a trip, it will just be closer to home.”

The wife of a couple who prior to her husband’s diagnosis, traveled extensively discussed the work of trying to regain their normal routine as well as their love for traveling in spite of the unpredictable nature of her husband’s heart failure:

“I push as much as I can to plan a trip, but I plan around (husband’s) condition. I have planned a short bus trip to New York City. If we take the bus, he will not be worried about me driving in the city, I have planned our walking route where I know there are lots of places to take a break. I used to never think of spending $6000 a piece on our trip, but now I am a bit more cautious as we have had to cancel a few planned trips. I do not act upset if we need to postpone due to (husband) but I do enjoying traveling.”

Negotiating required a complex balance by the caregiver. Negotiating entailed balancing the activities of the spouse. For some of the caregivers it was pushing to do more activities and for others it involved a negotiation of activities so as the spouse “would not over do it” in the eyes of the caregiver. Many of the spousal caregivers discussed the work involved in encouraging their spouse to resume normal activities as described in the following quotes:

“I am trying to get him to start to do things for himself- he was closing himself in and limiting himself. And yes he has to be careful.”
“He had not been driving because when they we adjusting his meds - his vertigo was so severe. Last week he did drive a short trip about 5 miles from our home to the bank and back. I’m always with him, I don’t let him go alone. And the next time we drove to the drugstore which is 20 miles maybe and that was the first long trip he made.”

“I try to give her little things to do and lately when I need to run errands, I take her with me, hopefully she will start to want to do things again and take some responsibility.”

“I put a puzzle out on the table, he used to love to do puzzles and I said to him when I had to run to the pharmacy, Do you want to come along?”

“I kind of started, very gently; pushing him into doing some things that he needs to do for himself. And it is even working. He seems to want to do some things for himself again which is good.”

For other caregivers, the work of normalcy required negotiation to take place on the part of the caregiver as they wanted a return to normalcy but were still concerned that resuming normal activities on the part of their spouse may elicit an exacerbation of symptoms. The work of negotiation was best exemplified by this quote from a 46-year-old female caregiver:

“Being a spouse and wanting to be supportive but not so much so that it puts him in jeopardy is a real tight walk to walk in at times - tightrope to walk at times. A
good example of that is how he ended up in the ER last March. It was a lovely day and I was working on a manuscript and he comes in in his jeans and work shirt and says I’m going to stain the deck. I’m like do you think that is a good idea? There’s this example of you want him to be independent, but you are thinking of how much physical activity is really involved here. Okay an hour, do it for an hour. Well an hour comes and goes and I haven’t seen him. All right, I better go and check on him. He’s still staining the deck but he looks as red as a tomato, sweat pouring off of him. I’m like you are done, you come sit in the chair and I need to take your blood pressure and your pulse which was through the roof.”

Regaining normalcy emerged from the data when the spouse was medically stable and was viewed by most as a positive experience. But, as highlighted by the quotes, normalcy required work on the part of the caregiver in terms of planning, anticipating and negotiating. The caregivers were also prepared for sudden and unplanned changes to normalcy as the unpredictable course of heart failure would change. In many cases, when these changes occurred the caregivers quietly dealt with the changes. As one caregiver said, “Nothing is certain, and I would never let him see how it upset me that our life has changed so much.”

**The Grounded Theory**

The seven main thematic concepts, *work of providing care, work of living with the illness, the work of navigating the system, the work of maintaining self, the work of managing the household, the work of vigilance, and, the work of normalcy*, support the basic social process of caring for a spouse across the illness progression of heart failure.
and informed the emergence of the core variable and subsequent theory. This emergence took place during the iterative processes of category reduction, identification of themes, sampling of the literature, and sampling of the data in support of the core variable. It was through these processes that the core variable, *committed obligation* emerged from the data.

The underpinnings of theory of Chronic Illness Management (Corbin & Strauss, 1988), enlightened the development of the grounded theory that emanated from the data provided by the study participants. The theory evolved as a result of integrative processes that began with the first analytical sweep through the data and continued until the analytic gestalt. This included the evolution of thinking that occurred over time through immersion in the data and the cumulative body of findings (Strauss & Corbin, 1998).

According to Glaser and Strauss (1967) the pertinent interrelated functions of theory are: 1) to enable prediction and explanation of behavior, 2) to be usable in practical applications in that prediction and explanation should be able to give the practitioner understanding and some control of situations, 3) to provide a perspective on behavior or a stance to be taken toward data, and 4) to guide and provide a style for research on particular areas of behavior (p.3). The discussion that follows in Chapter 5 will further enlighten these theoretical functions.

The experience of providing care to a spouse with heart failure was a complex process that occurred as the couple in tandem traversed the dynamic course of heart failure. The final result of all the analytical processes used in grounded theory is the development of a substantive theory grounded in the data collected from those living the

Review of the thematic descriptions supporting this process further explicated the meaning of this experience for the caregivers as the substantive theory of committed obligation emerged from the grounded data. All of the seven themes clustered together to analytically support the core variable of committed obligation. The core variable of committed obligation was grounded in the data by quotes from the caregiver including:

“As we go through all of this we do it together, I said I’ll stand by you, whatever we have to do and I meant that.”

“You’re committed to caring for her and she’s committed to care for you. It’s just being a caregiver for a patient with CHF it’s a life time commitment.”

“We knew what we had to deal with and we decided we wouldn’t sit down and we were gonna make it work.”

“Well when you love somebody you know it’s not a job it’s something that you don’t mind doing. You do it out of love you know.”

“It is a part of us, that’s just what you do.”

The middle range theory, *The Process of Committed Obligation*, emerged from the data as the most central pervasive aspect of the experience of providing care to a spouse with from the caregivers’ perspectives. This theory captures the complete story of
what takes place within the caregivers themselves as well as in the spousal relationship as the various types of work manifested in caregiving continued throughout the course of heart failure. The themes describe the basic processes that occur as the spouse provides care over a 12-14 month period of heart failure as well as support the emerging core variable of committed obligation.

Process

The first term, process, implies an ongoing series of changes that lead to a particular result. It is further described as a natural phenomenon marked by gradual changes that lead toward a particular result ("Merriam-Webster," n.d.), process also means to move along in. This definition aptly describes the experience of the spousal caregivers, for they were swept along and propelled by the course of the illness while at the same time subjected to continuous changes. They were engaged in the phenomenon of caregiving in the context of heart failure that imposed changes in their relationship leading to the emergence of the different types of work experienced while providing care to a spouse with heart failure.

Committed

The second term, committed, implies the spousal caregivers are entrusted in the relationship. Also described as to put in charge or trust, the term “committed” means to bind or obligate ("Merriam-Webster," n.d.). In the marital relationship described in this research, the spousal caregivers had not planned on being confronted with heart failure as well as the work involved in caregiving. But, as part of their commitment to their spouse, the caregivers provided the work of caregiving across the illness progression of heart failure.
Obligation

Finally, obligation is described as a binding promise, contract, or sense of duty ("Merriam-Webster," n.d.). This is an apt portrayal of the spousal caregivers in this study as they struggled to manage the various types of work experienced as they provided care to their spouse with heart failure.

The spousal participants in this study provided very detailed descriptions of their caregiving experience as well as the various types of work. Their descriptions also highlighted the process of managing the various types of work as part of their caregiving role and how their commitment to their spouse influenced this work. Living in the data and being immersed in the words that described their experience allowed the emergence of the grounded theory: The Process of Committed Obligation.

Grounded Theory: The Process of Committed Obligation

Spousal caregivers provided rich descriptions of the caregiving experience in the context of heart failure. From the spouses thick descriptions emerged the seven themes of work that summarized their experience as well as the core variable of committed obligation. Many painted a backdrop of commitment, happiness, and enjoyment with each other in the marriage. Shared meanings, life history, children, and in some cases grandchildren made up the mosaic of their lives. But in addition to their spousal relationship and lives together, the diagnosis of heart failure in a spouse imposed itself in the midst of their lives, and from then on, their lives changed.

In the face of such a deleterious force, the spousal caregivers were thrust into the unpredictable illness of heart failure. They described the work involved of caring for a spouse with heart failure and how the types of work varied dramatically as did their
spouse’s illness. They described accepting the diagnosis; and at times feeling helpless and out of control as the work of caregiving invaded all aspects of their spousal relationship.

The Process of Committed Obligation is the interaction of all of the types of work manifested in spousal caregiving surrounded by the core variable of committed obligation. The process is very dynamic as is heart failure. The process moves in tandem with the changes in the needs of the heart failure care recipient. The theory of the Process of Committed Obligation is best represented by the model below. It is important to note that although this model is static in its presentation, as part of the ever changing work of caregiving, the model is best represented as a dynamic model as noted by the circular arrows surrounding the wheel. The various types of work experienced in caregiving are represented as the spokes of a wheel that are theoretically rolling along as is the illness progression of heart failure. The hub, which is the mechanism that holds the spokes together, is the core variable of committed obligation. As you note from the model, the area located at the top of the wheel is not evenly spaced as the other spokes but is larger in area. This larger space is by design as it represents the work at the top of the wheel which is the work that is at the fore of consciousness for the caregiver at that point in time. It is the main type of work that is required in that specific point in time dependent on where the caregiver is in the illness progression of heart failure. As the caregiver continues, along with their heart failure spouse, throughout the unpredictable course of heart failure, the types of work at the top of the wheel dynamically change.
Figure 4.1: The Process of Committed Obligation

Although, one type of work may be priority and viewed as more important for the caregiver in that point in the trajectory, all of the spokes are linked together as the process of committed obligation. One would be remiss to focus on one aspect of work in isolation, as they all combined to illuminate the totality of the experience of caregiving.

Chapter Summary

The focus of this study was to explore the types of work experienced by spousal caregivers in the context of heart failure. This chapter has described the findings and the emergent theory that evolved from the data collected from the spousal participants. The grounded theory of the Process of Committed Obligation fully expresses the answers to the underlying issue of grounded theory studies- what is really going on here. Highlighting the experience of spousal caregiving and the types of work during the
unpredictable illness progression of heart failure greatly illuminates the need for specific interventions tailored to this population. Further discussion regarding the findings, the relationship to the current body of knowledge and potential for future research is addressed in Chapter 5.
Chapter 5
Discussion

Overview of Significant Findings

The purpose of this study was to gain a deeper understanding of the types of work experienced in long term spousal caregiving of older patients across the illness progression of heart failure specifically defining the types of work manifested over the course of 12-14 months of caregiving. The second goal of this study was to generate a middle range theory of spousal caregiving in heart failure. Seven themes emerged from the data as well as the core variable of committed obligation. The findings of this study provide a theoretical explanation of the work involved in providing care to a spouse with heart failure. The results also add a unique perspective to the extant body of literature reporting studies of spousal caregivers of care recipients with heart failure not previously reported in the literature. Descriptive of the changes over time, this study provides a global view of the various types of work manifested by the caregiver that occurred as the spouse lived with heart failure.

This study adds to what other researchers have reported in terms of the older caregiver experience by identifying the various types of work manifested based on the spouse’s heart failure illness. For every change in the spouses’ illness progression, the caregivers were impacted as well. The impact on the caregiver resulted in an emotive, physical or psychological response that was rarely addressed by the healthcare providers. The caregivers responded by providing care in concert with the ebbs and flows of the
care recipients’ illness throughout the ups and downs of heart failure. Each of the seven themes will be discussed in relation to the existing literature.

The work of living with the illness occurred throughout and was experienced in concert by both the caregiver and spouse. As one caregiver so fittingly summarized, “Although, I do not physically have heart failure, I have heart failure too.” This finding was confirmed by Callahan (2003) in a position statement advocating a family centered approach for families dealing with advanced heart failure. Callahan asserts that heart failure impacts both the patient and the family unit equally yet very differently. As the caregivers continued living with the illness, the finding of unmet needs was prevalent in the detailed descriptions provided by the caregivers. The caregivers spoke of a need for more information and uncertainty regarding heart failure with statements such as, “I know no one knows what will happen but we do not want to hear he is stable every month- that just isn’t enough,” and “If I do not have my list prepared the conversation would start and end with you are doing well this month keep it up.” Consistent in the findings of this study, the participants did not view healthcare professionals as a source of adequate information as they attempted the work of living with the illness.

The work of providing care encompassed both the physical and psychological provisions of care provided by the spousal caregiver. It was very evident from the finding that caregivers wanted to do a good job in terms of providing care. Providing care well is important to caregivers and developing caregiving competency, knowledge and skill is a central concern for those in the caregiving role (Brown & Stetz, 1999). The knowledge of providing care, symptom management, and what signs and symptoms to report seldom originated from healthcare providers, but came from firsthand experience.
While the spousal caregivers were committed to their role, they did so from a limited clinical or formal knowledge base and were frequently seeking out sources of information. These findings suggest that support for spousal caregivers should focus on increasing the caregiver’s understanding of the condition and its management and should enhance their capacity to work with patients around disease management (Boyd et al., 2004). While healthcare providers involvement in heart failure management programs increase the likelihood of improved outcomes (Yu et al., 2006), few of these programs address the needs of the caregiver (Clark et al., 2007). Yet, there is a growing body of research on the need of caregiver support as well as information. Given et al. (2008) found that providing caregivers with information about managing patient’s symptoms can help alleviate the uncertainty regarding decision-making in the home setting. Evangelista et al. (2002) reported that when caregiver’s needs are met via ongoing communication and interventions designed to address the caregiver’s ability to perform the caregiving tasks associated with heart failure, their emotional well being is improved which was an independent predictor of patient emotional well being.

The work of normalcy encompassed all of the work by the caregiver to establish some type of routine or normal in everyday life. The findings revealed the work of negotiating with the spouse and at the same time maintaining a balance in an attempt to establish some type of normal routine manifested by flexible planning in light of the alterations imposed by heart failure. In times of relative stability the participants spoke of their attempts to foster more independence in the care recipient. Clark et al. (2007) described this phenomenon in which caregivers responded to patients’ capacities and adopted strategies that fostered independence as well as normal life for the patient that
was possible and safe. Some of the participants talked about the risk of providing “too much care” for the care recipient when they were more stable, and thus left tasks for the care recipient based on their judgment of which activities they should be able to perform on a particular day.

The *work of managing the household* was another area of prominent findings from the study, which is attributed to the longitudinal design. The work continued throughout the course of heart failure. Even in the most medically stable of times, some type of work related to heart failure continued on the part of the caregiver. It is often during these times of medical stability that the work of the spousal caregiver goes unnoticed by healthcare providers. During times of stability the caregivers spoke of issues such as, “*now I am going through the stacks of bills*” and “*When he was sick, I never paid attention to the yard, that was his work and now it is mine.*” Previous research supports this finding of the day-to-day impact and disruptions of caring for a patient with heart failure (Luttik et al., 2007; Mahoney, 2001; Pattenden, Roberts, & Lewin, 2007).

The *work of vigilance* was expressed as the constant monitoring and watchfulness that occurred throughout the experience of caregiving. These results add to what other researchers have found in terms of the constant monitoring on the part of the caregiver. Caring has been described as a complex emotional relationship of responsibility that has developed in the role of spousal caregivers and is manifested as concern and deeper insight into their partner’s needs in light of their changing health conditions (Cheung & Hocking, 2004). Vigilance is defined as the caregiver’s continual oversight including activities such as watchful supervision, anticipating, and as a 24 hour responsibility
(Mahoney, 2003). Even in times of medical stability, the caregivers in this study were constantly monitoring their spouse for any changes in condition and were very astute to subtle changes such as alterations in facial expressions, appearance, complexion, and mood. Whereas healthcare providers base care primarily on clinical signs and symptoms, the care provided by spousal caregivers was based on awareness of the care recipient arising from long term monitoring. This expertise on the part of the caregiver was reported by Clark et al. (2007) as the “visible and invisible” care activities.

The work of maintaining self was rarely a priority in the discussions by the participants in the study and if it was discussed it was during times of relative medical stability in the care recipient. The physical impact of caregiving is well documented (Lieberman & Fischer, 1995; Navaie-Waliser et al., 2002; Teel & Press, 1999) as well as the psychological impact (Braun et al., 2007; Cheung & Hocking, 2004; Martennson, Dracup, Canary, & Fridlund, 2003) yet was not frequently addressed by the participants. When the caregivers did discuss the issue of their health or seeking care it was during a medically stable time for the care recipient. The busy caregiving schedule or perceived lack of support may result in the caregiver neglecting his or her own self care (Schulz et al., 1997). Shaw et al. (1997) reported a similar finding of a reluctance among caregivers to schedule hospital care at times when the spouse appeared to have the greatest caregiving needs. This finding has important implications for health care providers and speaks volumes for the necessity to embrace caregivers as co-providers and co-recipients of care.

As the work of navigating the system was manifested in the data by the caregivers, many unmet needs on the part of the caregivers were identified. The unmet
needs of the caregiver are consistent with the view that caregivers are not viewed as co-providers of care. Buetow (2004) in his essay advocates viewing caregivers as co-providers of care and views this reconceptualization as a means to acknowledge the lay influences on care, as well as a means to achieve better coordination and comprehensiveness of care. The findings of this study supported the position that caregivers are not viewed as co-providers of care. Statements such as, “I never feel welcomed [referring to doctor’s office] I feel like I am actually imposing because I ask the questions.” Luttik and colleagues (2007) reported that caregivers did not feel involved or informed by healthcare providers in the care of the heart failure patient. Caregivers reported even when present for discussions by the healthcare team, their presence was rarely acknowledged. This finding was also confirmed by Molloy et al. (2005) who found that research into discharge planning and discharge support for heart failure patients proceeded for the most part without the inclusion of the informal caregivers as part of the research design. Not only are caregivers not included as part of the research design, they are not involved as a component of home based interventions for heart failure patients (Gonseth et al., 2004). Not including the spousal caregiver in communications with the health care team results in feelings of isolation and decreased involvement in the care of the patient in the home setting (Martennsson, Dracup, & Fridlund, 2001). In addition, supportive relationships and emotional support of the caregiver have been demonstrated to improve outcomes for heart failure patients (D’Alto, Pacileo, & Calabro, 2003; Saunders, 2008).

It was illuminated from the data as the caregivers continued the work of navigating the system, that heart failure management is a complex process requiring
coordinated, supportive care. Similar to the findings of unmet needs, caregivers described a “lack of coordination” as well as “feeling lost in the system.” This issue would be best addressed with comprehensive supportive care models. Aldred et al. (2005b) recommended professional input and care for heart failure similar to those diagnosed with “more familiar terminal diseases.” The call for comprehensive supportive services for heart failure similar to a palliative care model is not new in the literature. In fact, the literature is abundant with recommendations and consensus statements to implement palliative care models (Fitzsimons et al., 2007; Gibbs et al., 2002; Goodlin et al., 2004) and even proposed models of care (Daley, Matthews, & Williams, 2006; Hupcey, Penrod & Fenstermacher, 2009; Stuart, 2007). Although the concept of this comprehensive care model is not new to the literature, the implementation of a comprehensive supportive model of care did not exist in this sample.

**Findings in Relation to the Model**

The Chronic Illness Management Theory (Corbin & Strauss, 1988) was used to frame this study. The figure from the Corbin and Strauss model (1988) is depicted below for reference.
Utilizing this theory as the interpretive lens for the data, the seven themes (the work of providing care, the work of living with the illness, the work of navigating the system, the work of maintaining self, the work of managing the household, the work of vigilance, and the work of normalcy) emerged from the data. Additional analysis and theoretical insights illuminated the core variable of committed obligation as well as the middle range grounded theory *The Process of Committed Obligation*. This theory represents a phenomenon experienced by the study group throughout the caregiving course of heart failure. Corbin and Strauss (1988) viewed the work of spousal caregiving as a process or interaction between the spouses. Each of the seven identified work
themes, support the premise of a process or interaction between the spouses in the context of heart failure. As the work of Corbin and Strauss was evaluated in the context of the findings of this study, it was apparent from the model that the glue that held the couple together was not evident and led to the insight of the core variable of committed obligation as an extension of the Chronic Illness Management Theory.

This theoretical insight is described by Glaser and Strauss (1967) as they describe the process of theory generation:

Theory is a strategic link in the formulation and generation of grounded formal theory. We believe that although theory can be generated directly from the data, it is most desirable, and usually necessary, to start the theory from a substantive one. The latter not only provides a stimulus to a good idea, but it also gives as initial direction in developing relevant categories and properties and in choosing possible modes of integration. (p.79)

This middle range theory grounded in the data, weaves all of the identified themes of work together. The tapestry is held together by the core variable of committed obligation and collectively presents a basis for understanding the significance of spousal caregiving in the context of heart failure. As one evaluates Figure 5.2, the influence of the guiding conceptual model is evident.
The complex work of caregiving is evident in the holistic model. All of the seven identified themes comprise the role of the caregiver. The emerging research on caregiving as a complex role is significant for nursing practice. This complex role is not well addressed in the current body of caregiving literature and the role should not be defined solely as tasks or procedures. The findings support existing research that caregiving is much more comprehensive than the visible tasks but also includes invisible tasks (Clark et al., 2007). It has been suggested that healthcare providers should assess multiple caregiving processes and target their interventions to processes with which the caregiver needs help (Schumacher et al.).

Understanding what is happening in the lives of the caregivers provides a basis for determining interventions appropriate to their special needs. This theory provides
healthcare care professionals with added knowledge of the caregiving process as well as the types of work experienced by the caregivers in the context of heart failure. It is important for healthcare providers to view the model holistically. As one type of work is experienced as the predominant type of work at that point in the course of the illness, it does not occur in isolation but in conjunction with the other types of work. The model adds and advances the existing research of spousal caregiving in heart failure in that few studies were identified that investigated the complex nature of the caregiving role.

Understanding the caregiving role has remained superficial, task-oriented, and underdeveloped especially in exploration of the complexities of informal chronic disease management (Clark et al., 2007). This holistic and comprehensive model expands the scope of research from a limited focus to the whole constellation of caregiving tasks, processes, and knowledge comprising the caregiving role.

**Implications of the Findings**

This study has significance for the practice of nursing by providing a new awareness of the types of work involved in the process of spousal caregiving within the context of heart failure. Healthcare professionals who care for heart failure patients could significantly impact the experience for both the caregiver and the spouse living with heart failure by recognizing they are both co-recipients of care as well as acknowledge the various types of work involved in caregiving. The results of this study demonstrate that the needs of the couples, especially the caregiver, require more than a brief contact with the healthcare provider and healthcare providers should recognize cues in the clinical encounters that could lead to specific needs driven interventions. The findings of this study illustrate that the caregiver moves with the spouse during the course of the illness.
and when there is an exacerbation or instability the needs of the caregiver escalate in tandem with the care recipient but may be manifested in different ways. An example is that patient awaiting a heart transplant in the hospital has very acute medical needs. The needs of the caregiver are just as acute but deal with the work of maintaining the household (which could be at a distance), finances, the work of vigilance, as well as living with the illness. The needs of the caregiver are just as significant and acute as the medical needs of the care recipient and occur throughout the entire course of the illness even during times of stability. These needs must be anticipated and addressed with specific interventions by healthcare providers. This heightened awareness of the specific and changing needs of the caregiver is expected to inform nursing interaction and supports the development of future research and implementation of evidence based practice.

The information provided by this study enhances health care providers’ ability to more accurately assess the needs of the spousal caregivers and thus determine and implement appropriate supportive care measures. This study highlighted an added dimension of knowledge that healthcare providers can use to develop and enhance supportive care and effective interventions geared toward meeting the specific unmet needs of the caregiver as they occur across the trajectory of heart failure.

The results from this study and the resulting middle range theory, *The Process of Committed Obligation*, which emerged in this study, augments nursing knowledge of the work involved in the part of the spousal caregiver. The various types of work experienced during the illness informed the resulting themes, the core variable as well as the substantive theory. These results offer a new understanding of the basic social process
that is occurring in the role of the caregiver and therefore, provides a theoretical basis for
the development of nursing interventions specific to the special needs of this caregiving
population.

The results of this study will add to the existing body of knowledge in the
caregiving field and potentially serve as a conceptual model to frame the research of
others who are interested in the dynamic role and work involved in caring for a
chronically ill spouse. With the generality of the middle range theory, it is theoretical
possible to utilize and extend this theory not only with other chronic illnesses but also
with caregiving roles that are not spousal in nature but share a commitment bond such as
caring for a parent or child with a chronic illness.

Approximately 5.8 million people are living with heart failure and it is estimated
the incidence of heart failure after the age of 65 approaches 10 cases per 1,000
populations (Lloyd-Jones et al., 2010). Heart failure patients are defined with physical
limitations, frequent hospitalizations, and a high risk of mortality. Compounding this
issue is the lack of prognostication due to the unpredictability of the illness. As the
general population ages and new technology extends the lives of cardiac patients, the
prevalence of heart failure is expected to increase. It is imperative that nurses develop
interventions that will support those in the caregiving role. Nurses have pivotal roles as
providers of care to those patients and caregivers impacted by heart failure and must take
a leadership role in disseminating research findings to caregivers as well as other health
care providers. The findings from this study enhance nursing’s understanding of the need
for additional support and specific needs driven interventions directed at this special
population.
Study Strengths and Limitations

The longitudinal design was a strength of this study as it enabled the researcher to capture the dynamic nature of the heart failure trajectory over time. Most of the 20 spousal participants of care recipients over the age of 62 were interviewed approximately every month over a period of 12-14 months. The rich, detailed data provided by the spousal participants enhanced the researcher’s ability to analyze the data as well as the emergence of the resulting grounded theory.

Another strength of the study was the diversity of care settings represented in the sample. The heart failure care recipients were cared for in a variety of setting from major tertiary referral centers, to the local cardiologists, to family practice physicians, and finally a combination of the three. Variation also existed is the distance the patients and caregivers traveled for care and the resultant impact that had on the work of caregiving.

A panel with qualitative experience was utilized to confirm the themes as well as the emerging theory. Not only did the panel have expertise in qualitative methods, they also were familiar with the original data set utilized for the secondary analysis.

A limitation of this study is that participants were primarily Caucasians. Future qualitatively derived studies involving spouses from various ethnic and racial backgrounds in the context of heart failure would add meaningful data to help provide culturally sensitive care. The caregivers (mean age of 67) were all providing care to spouses over the age of 62. It would be important for future studies to include participants with a greater variation in age range.
The spousal caregivers in this study were for the most part healthy. Any health issues reported by the caregivers did not impact their ability to provide care. Additionally any issues that did require intervention were not emergent but elective procedures and were scheduled when the care recipient was medically stable. The good health status of the participants would limit the generalizability of the results. A study that included participants with variations in health status is important for future studies.

As study findings were related to the literature, an additional limitation emerged. All of the participants in this study reported having a happy and lengthy marriage. As the literature suggests that prior marital satisfaction may play a role in caregiver attitude and burden, it is recommended that future studies include participants with more varied martial backgrounds (Edwards & Scheetz, 2002; Goldstein, Atkins, Landau, Brown, & Leigh, 2006; Seltzer & Li, 2000).

The final limitation of this research is the use of secondary analysis as a method of grounded theory. According to Glaser (1978), theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data. Although within the large data set, saturation of the themes was achieved, in a secondary analysis theoretical sampling is not possible in the purest sense and should be viewed as a limitation of the study.

**Recommendations for Future Research**

An intervention study implementing strategies directed specifically to the predominant type of work manifested at a specific point in the trajectory could perhaps lead to improved role performance with less uncertainty for the spousal caregivers. Specific needs driven interventions that account for the needs of the patient and caregiver
as co-recipients of care may empower the spousal caregiver and help achieve a sense of mastery in their role.

**Research Based on Emergent Theory**

The findings of this study add depth and knowledge to spousal caregiving in the context of heart failure as well as the types of work experienced throughout the course of the illness. The emergent middle range theory provides a new perspective of the work of caregiving in the context of heart failure and could be enhanced by additional confirmative research. Research directed toward further delineation of the theoretical conceptualization is recommended. Continued development and validation of the theory should guide future inquiry. Research directed at validating the emergent theory in a different chronic illness or with a different committed bond such as caring for a child or parent is also recommended.

**Conclusions**

This research was conducted in search of an understanding of the experience of the work of spousal caregiving in heart failure. Tenets of the grounded theory approach were utilized to ascertain the experience of those whose lives were enmeshed in the reality of the study’s focus. The participants provided detailed accounts of the realities confronted during the course of the illness. Rich with emotion and descriptive detail, the data readily informed the emergent theory. *The Process of Committed Obligation* embodied the experience of spousal caregiving across the illness progression of heart failure. The themes highlighted the work involved in providing this care and enlightened the core variable of committed obligation. The perspective on work as well as the commitment to this work in the context of the spousal relationship contributed to a new
point of view in spousal caregiving. Spousal caregiving in the context of heart failure is more dynamic and multifaceted than presented in the current body of literature. The complexity of this task is compounded by the unpredictable course experienced by the spouse. The caregiver moves in tandem with the spouse with various types of work experienced during both medically stable and acute periods of the heart failure illness.

The health and well being of these spousal caregivers is potentially threatened and in need of specific interventions. It is imperative for healthcare providers to view the spousal caregivers as co-providers and co-recipients of care. It is also vital for healthcare providers to recognize that there are unmet needs for the caregiver and these needs change across the course of heart failure and would be best addressed with a comprehensive supportive care model initiated early in the course of heart failure.

This study captured a new meaning and understanding of this unique caregiving situation and thus revealed the context in which to guide future research toward the development of interventions and needs driven strategies that will target the special needs of spousal caregivers of partners with heart failure.
References


Evangelista, L. S., Dracup, K., Doering, L., Westlake, C., Fonerow, G. C., & Hamilton,


Lindgren, C. L. (1990). Burnout and social support in family caregivers. *Western*
Journal of Nursing Research, 12, 469-487.


Dying of lung cancer or cardiac failure: Prospective qualitative interview study of patients and their carers in the community. *British Medical Journal, 325,* 929-933.


Schulz, R., McGinnis, K. A., Zhang, S., Martire, L. A., Herbert, R. S., Beach, S. R.,


Appendix A

Recruitment Flyer Hupcey Study

The Pennsylvania State University
School of Nursing
600 Centerview Drive
1300ASB/A110
Hershey, PA 17033

Patients with Heart Failure & Their Family Caregivers

- Nurses from Pennsylvania State University, School of Nursing, under the direction of Judith E. Hupcey, Ed.D., CRNP, are conducting a study to help us understand:
  - What it is like to care for a person with heart failure; and
  - What it is like to live with heart failure.
- Research volunteers are sought for this study.
- Participation in this research involves talking with a researcher about your experiences as a caregiver or a person with heart failure.
- This research may benefit future patients and families in similar situations.
- We estimate that the initial interview will take between 60 and 90 minutes and subsequent phone interviews will last approximately 30 minutes.
- Participants will receive financial compensation for each interview they participate in.
- If you are considering taking part in this study, you may contact Judith E. Hupcey at (717) 531-4211.

This research has been approved by the Institutional Review Board, under federal regulations, at Penn State Milton S. Hershey Medical Center, Penn State College of Medicine.
IRB # 22307EP [Version Date: 9/12/2006]

Please complete and tear off bottom portion and give to your doctor/nurse in clinic or the researcher.
Appendix B

Consent Form Hupcey Study

CONSENT FOR RESEARCH
Penn State College of Medicine
The Milton S. Hershey Medical Center

Title of Project: Comprehensive Palliative Care For Patients with Heart Failure and Their Family Caregivers

Principal Investigator: Judith E. Hupcey, EdD, RN
Associate Professor of Nursing

Other Investigators: 
Janice Penrod, PhD, RN
Assistant Professor of Nursing
Janet Fogg, MS, RN
Instructor of Nursing
Research Assistant
Barbara Biddle, PhD(c), RN
Graduate Research Assistant

John Boehmer, MD
Professor of Medicine
Lisa Kilk, MS, RN
Instructor of Nursing
Research Assistant

Participant's Printed Name: __________________________

This is a research study. Research studies include only people who want to take part. This form gives you information about this research, which will be discussed with you. It may contain words or procedures that you don't understand. Please ask questions about anything that is unclear to you. Discuss it with your family and friends and take your time to make your decision.

1. Purpose of the Research:
   You are being offered the opportunity to take part in this research because your family member has a diagnosis of heart failure. The purpose of this research is to have family caregivers discuss their experiences caring for a family member with heart failure so that we may get a better understanding of the experiences and needs of patients and families during these times. Approximately 120 participants will be enrolled.

2. Procedures to be Followed:
   You will be asked to participate in a tape-recorded interview about your caregiving experiences.
• If you agree to participate this is what you can expect:
  1. You will be asked to read and sign this consent form.
  2. A member from the research team will set up a time and place, appropriate for you, to do the initial interview.
     • If the family member is hospitalized at the time of the interview, we will direct you to a private area within the hospital where the interview will take place.
     • If the family member is not presently hospitalized and you decide to meet at the Hershey Medical Center, you will be directed to a private conference room where the interview will take place.
     • If the family member is not presently hospitalized and you want us to come to your home, we will conduct the interview in a quiet, private area of your home.
  3. You will be interviewed about your experiences caring for a family member with heart failure. You do not have to answer any questions that make you uncomfortable.
  4. You may be asked if we may contact you monthly for up to one year by phone to see how your caregiver experience is going and if there have been any changes in your caregiver status.
  5. If changes occur with the family member (such as earlier clinic visit or hospitalization a staff member from the heart failure service will notify us and we will contact you) or in caregiving, we will do an in person interview with you at a time and place of your convenience.
  6. All interviews, face to face and by phone, will be audiotaped.
  7. Your name or any other identifying information will be removed from the taped interview during transcription.

3. Discomforts and Risks:
   Potential loss of confidentiality
   As you talk about the family member’s illness, you may feel emotional as memories and situations are relived. Or you may tire and need to stop the interview sooner than expected.
   If these situations occur you may:
   • Stop the interview.
   • Restart the interview when you are ready and agree to continue.
   • Be asked to make another appointment to continue the interview at a later time.

4. Possible Benefits:
   • Possible benefits to the participant:
     • You may not benefit directly from taking part in this research study.
   • Possible benefits to others:
     • Information from this research may be used to develop interventions that may help other patients and families in a similar situation.

5. Other Options that Could be Used Instead of this Research:
   • You do not have to take part in this research study.
6. **Time Duration of the Procedures and Study:**
   - If you agree to participate in the study, your first tape-recorded interview will last 60-90 minutes.
   - After the first interview, we may call you every month for up to one year to conduct about a brief 30-minute tape-recorded interview.
   - If you agree to participate in the one year study and there are changes in your caregiving experiences or if your family member needs to return to the clinic earlier than expected or is readmitted to the hospital, you will be asked to do an in person interview with you at your earliest convenience.
   - In the event that your family member dies before the end of the study, we will contact you for permission to complete one final interview at your convenience.

7. **Statement of Confidentiality:**
   - **Privacy and confidentiality measures:**
     1. You will be interviewed (audio recorded) by a member of the research team.
     2. Your audiotape will be labeled with a code, date, and time.
     3. The principal investigator and co-investigators will have access to the list that links the code number to your name, which will be kept separate from the audio taped interviews and transcripts.
     4. Any information in the data that can identify you will be removed as tapes are transcribed.
     5. The person who transcribes the tapes will not have access to your name, but will have access to the tape recording with potentially identifying information.
     6. The transcripts will be reviewed and analyzed by the research team only.
     7. Your taped interviews and transcripts will be secured in a locked file at The Pennsylvania State University, School of Nursing.
     8. The tape recorded interviews will be destroyed following transcription.
     9. In the event of any publication or presentation resulting from the research, no personally identifiable information will be shared.
    10. We will keep your participation in this research study confidential to the extent permitted by law. However, it is possible that other people may become aware of your participation in this study. For example, the following people/groups may inspect and copy records pertaining to this research:
        - The Office of Human Research Protections in the U. S. Department of Health and Human Services
        - The HMC/PSU Institutional Review Board (a committee that reviews and approves research studies) and
        - The HMC/PSU Human Subjects Protection Office
        - PSU College of Health and Human Development, the sponsor of this research
   - Some of these records could contain information that personally identifies you. Reasonable efforts will be made to keep the personal information in your
research record private and confidential but absolute confidentiality cannot be guaranteed.

8. Costs for Participation:
   • There will be no cost for participating in this study. You are not waiving any legal rights you may have by signing this form.

9. Compensation for Participation:
   • You will receive a $10.00 gift card for each interview in which you participate.

10. Research Funding:
    • The investigators are receiving a grant from Penn State's College of Health and Human Development and the American Heart Association to support this research study.

11. Voluntary Participation:
    • Taking part in this research study is voluntary. If you choose to take part in this research, your major responsibilities will include being available at the agreed upon location, at a specific time, to be interviewed by a member of the research team for approximately 30-90 minutes. You do not have to participate in this research. If you choose to take part, you have the right to stop at any time. If you decide not to participate or if you decide to stop taking part in the research at a later date, there will be no penalty or loss of benefits to which you are entitled.

12. Contact Information for Questions or Concerns:
    • You have the right to have all of your questions and concerns addressed.
    • You may contact the PI, Dr. Judith Hupcey, at (717) 531-4211 if you have further questions, complaints or concerns about the research.
    • If you have questions regarding your rights, as a research participant or you have concerns or general questions about the research contact the research protection advocate in the HMC Human Subjects Protection Office at 717-531-5687. You may also call this number if you cannot reach the research team or wish to talk to someone else.
    • For more information about participation in a research study and about the Institutional Review Board (IRB), a group of people who review the research to protect your rights, please visit the HMC IRB's Web site at http://www.hmc.osu.edu/irb. Included on this web site, under the heading "Participant Info", you can access federal regulations and information about the protection of human research participants. If you do not have access to the Internet, copies of these federal regulations are available by calling the HSPO at (717) 531-5687.

Signature and Consent/Permission to be in the Research
    • Before making the decision regarding enrollment in this research you should have:
      • Discussed this study with an investigator.
Reviewed the information in this form.
Had the opportunity to ask any questions you may have.
Your signature below means that you have received this information, have asked the questions you currently have about the research and those questions have been answered. You will receive a copy of the signed and dated form to keep for future reference.

**Participant:** By signing this consent form, you indicate that you are voluntarily choosing to take part in this research.

__________________________  ______  ______  ________________
Signature of Participant     Date      Time      Printed Name

**Person Explaining the Research:** Your signature below means that you have explained the research to the participant/participant representative and have answered any questions he/she has about the research.

__________________________  ______  ______  ________________
Signature of person who explained this research  Date      Time      Printed Name
(Only approved investigators for this research may explain the research and obtain informed consent.)
Appendix C

Interview Guide Hupcey Study

Hupcey
Updated 11/03/06

Family Caregiver

Insert into interview the following Short narrative-

This the interview AHA F1.1JH, 1st in-person – hospital or home [describe the home] (or phone) interview with the 52 year old wife of a 58 year old pt with heart failure. The pt was diagnosed ---, he has an implantable defibrillator, or what ever (1-2 sentence summary- can be inserted after the interview is completed)

Initial Interviews will begin with descriptive information including:

- Age
- Ethnicity
- Occupation
- Travel time to clinic/doctor
- Length of time since the patient’s diagnosis with heart failure
- Characteristics of the care-recipient’s health status
- Health status of the caregiver
- Types of assistance provided by the caregiver.
- Financial Impact

Initial interview questions:

- Tell me about your experiences providing care to _____.
- Are there things that you do that the care-recipient once did?
  - Are the number of additional activated increasing?
  - How has this affected your life?
  - Are you able to do these in addition to your normal activities? (getting at not going out with friends, missing work, having to change jobs to meet care-recipients needs.
- Do you receive help from anyone with these activities?
- Have there been things (services) that you have needed as a caregiver that you felt that you have not received?
- At what point would these _____ have been helpful?
• Do you think your family member would have wanted these same services (at the same time)?
• Who do you go to for help and support?
  • Supportive network
  • Have you called them in?
  • Did you call them in?
    o How did it work?
• Mood- what triggers mood changes?
  o Describe what was going on.
  o Pre-illness temperament
  o How do you mange them?
• What do you expect from his present treatment?
• Where do you see yourself and ___ in a year?
• Planning for future events (eg vacations).
  Probes:
  • Can you explain how you felt during that time?
  • Tell me more about that experience.

  Follow-up Interviews:
  • Tell me about your caregiving experiences since we last talked. or
  • Tell me what has been going on with ____ since our last interview.
  • Over the last month have you noticed a need for other services?
VITA

Lisa Ann Kitko, RN, PhD, CCRN

Home Address: 5788 Green Acre Road
Houtzdale, PA 16651
Email: lah150@psu.edu

Education:
2010 PhD in Nursing, Gerontology Minor
The Pennsylvania State University, University Park, PA
2001 Master of Science, Clinical Nurse Specialist
The Pennsylvania State University, University Park, PA
1990 Bachelor of Science in Nursing
The University of Pittsburgh School of Nursing, Pittsburgh, PA

Professional Experience:
8/2000-Present: Campus Coordinator and Nursing Instructor, The Pennsylvania State University, School of Nursing, University Park Campus
8/2005-8/2008 Research Assistant, Dr. Judy Hupcey, The Pennsylvania State University, School of Nursing, University Park Campus
3/1999-8/2000 Administrative Director, Neurovascular Services, Altoona Hospital, Altoona, PA
5/1992-3/1999 Charge Nurse Medical Intensive Care, Altoona Hospital, Altoona, PA
5/1990-5/1992 Staff Nurse, Intensive Care, Hershey Medical Center, Hershey, PA

Journal Articles


Book Chapters